

Mojca Ramšak*

Medical Racism

SUMMARY

The article analyses key examples of unethical medical experimentation on humans. The first part deals with racism, its ideology, and connectedness with concepts of medical racism. Concepts of the race that first emerged during the colonial expansion were defined by following their origins and function and not the philosophical thought. The second part builds upon the autonomy of patients. It includes the right to informed consent, protection of privacy, right of confidence, and persons with limited autonomy, all from a historical perspective on medical racism. In this section, the selected cases of medical racism show that the development of legal regulations and ethical norms importantly influenced the medical practice and the protection of subjects. The historical evidence also witnesses that even if the formal protection existed, there were deviations from it. The deviations were closely related to socio-political regulation and the rapid development of medicine that was a step before ethical norms. Additionally, war crimes against humanity were connected with personal ideological orientations of doctors whose racist, discriminatory beliefs were far beyond medical ethics and the purpose of medical practice. In the end, the article deals with the questions whether the results from unethical and unscientific experiments should be used and in what way medical racism endangers vulnerable groups today.

Keywords: medical racism, medical ethics, human experimentation, institutional racism, history of medicine.

I. Introduction: On race, racism and racialism

The term *race*¹ first appeared in the 16th century and was used to pick out and group people based on their looks, customs, origin, or ancestry. In the 18th and

* *Correspondence Address:* Mojca Ramšak, University of Ljubljana, Faculty of Medicine, Institute for History of Medicine, Zaloška 7a, 1000 Ljubljana, Slovenia; and University of Ljubljana, Faculty of Arts, Department of Ethnology and Cultural Anthropology, Zavetiška 5, 1000 Ljubljana, Slovenia. E-mail: mojca.ramsak@guest.arnes.si.

1 All the emphasis was added by the author.

19th centuries, race acquired a specific biological meaning, and the groups picked out as different races came to be viewed as different subspecies or lineages of man. The biological concept of race was accompanied by the belief that members of some races are superior in ability or virtue to members of others and was often invoked to justify the control of one group of people by another and, in particular, to defend the Atlantic slave trade and the colonization of Africa and Asia by the countries of Europe. Biological conceptions of race persist and, though contested by social as well as biological scientists, continue to shape how race is understood or talked about.²

Racism is the theory that people can be put into categories based on their physical appearance – skin colour, hair, texture, shape of the face – and that those physical categories also serve to define those people’s intelligence, attitudes, and behavioural traits. The end result of this process of categorisation is that races are ranked on a ladder of worth, with people belonging to some races declaring themselves to be superior to people belonging to other races.³ Lay people in many different cultures tend to conceive of races in biological terms. That is, racial membership tends to be viewed as biologically inherited, causing people to possess various race-specific physiological traits (such as skin colour or body build), and even some psychological and behavioural ones (such as a distinctive temperament or character, which mix violence, laziness, limited intelligence, and lust). Socialisation can weaken the common and early developing biological conception of race, a distinction between an early-developing disposition to classify into races and to think of them biologically (“racialism”), on the other hand, it can also reinforce and culturally sanction it.⁴ *Racialism* is the idea that classifications made on the basis of some visible physical features (skin colour, height, hair, dialect, etc.) have a biological reality. It must be distinguished from the racism that adds value judgements (mostly negative, but sometimes positive) to racialism.⁵

The “traditional” division of the human species into three races (“Caucasian,” “Mongoloid,” “Negro”) is inherently arbitrary and culturally constructed, but it has very real and tragic consequences. Modern racism was born with the rise of African slavery in the Americas and the simultaneous spread of European empires. Europeans

2 Root, Michael (2017). Race in the Biomedical Sciences. *The Oxford Handbook of Philosophy and Race*. Oxford University Press, 463.

3 Skutsch, Carl (2001), Racism. *The Human Rights Encyclopedia*, Volume Three. Carl Skutsch, James Lewis (Eds.). Sharpe Reference, 855.

4 Machery, Edouard (2014). Social versus Biological Conceptions of Race. *The Wiley Blackwell encyclopedia of health, illness, behavior, and society*. (Eds.) William C. Cockerham, Robert Dingwall, and Stella R. Quah. John Wiley & Sons, Ltd., 2137.

5 Machery, Edouard, Faucher, Luc (2004). Why do we Think Racially? A Critical Journey in Culture and Evolution. H. Cohen C. Lefebvre. *Categorisation in Cognitive Science*, Elsevier, 2. https://jeannicod.ccsd.cnrs.fr/ijn_00000531/document, accessed, January 28, 2020.

justified their enslavement of Africans by arguing that the Africans were inherently inferior, that they naturally were racially beneath the Europeans. When Europeans went on to conquer much of the world during the 17th, 18th and 19th centuries, they justified their conquests using the same racial ideas: they believed that they were entitled to conquer non-Europeans, because they considered themselves racially superior.⁶ Similarly, in the United States, racism is the product of colonization and slavery. With an increased desire for profits from agriculture, settlers wanted more slaves. And with ideas of freedom and equality written into the *Declaration of Independence* (in the claim that “all men are created equal”, 1776), a justification and legalization of the institution of slavery and simultaneously a way to legitimize racism, especially institutional racism, was needed. To increase and maintain a large, cheap labour force, the rights of blacks and other people of colour were eliminated.⁷ In 1858 the phrase “all men are created equal” from the *Declaration of Independence* became disputed, because some believed that it referred to white men only. For them, the purpose of the Declaration had simply been to justify the independence of the United States, and not to proclaim the equality of any “inferior or degraded race”.⁸ A legacy of this chapter in the United States history is continued beliefs about minorities as diseased populations with lowered mental abilities.⁹

Racial categories were developed by Johann Friedrich Blumenbach (1752–1840), a German professor of medicine, who started examining the cranial differences between the five *racēs* (American, Mongolian, Ethiopian, Caucasian, and Malay). In his dissertation (*On the natural variety of mankind*, 1795), he put forward the theory that divided all human beings into five races: Mongoloid, Ethiopian, Caucasian, American, and Malayan.¹⁰ Blumenbach had no scientific basis for his categories; they were based entirely upon appearance. His ideas were expanded upon by the 19th-century French writer Joseph de Gobineau (1816–1882), who argued (in *Essai sur l'inégalité des races humaines*, 1853–55) that the white race was superior to all other races (something Blumenbach had never said).¹¹ This pseudo-scientific research tradition became central to 19th-century anthropology. Cranial measurements were thought to provide grounds for an objective racial hierarchy. These biological classifications of races, which distinguished races on the basis of physiological and temperamental features, often justified claims about the superiority of some races

6 Skutsch, Carl (2001), *Racism*, 855.

7 Hutchinson, Janis Faye (2008). *Medical Racism. Encyclopedia of Race and Racism*. Vol. 2, g–r. John Hartwell Moore (Ed.). Thomson Gale, 293.

8 Maier, Pauline (1998), *American Scripture: Making the Declaration of Independence*. Vintage Books, 204.

9 Hutchinson, Janis Faye (2008), 293.

10 Machery, Edouard (2014), 2138.

11 Skutsch, Carl (2001), 856.

over others (though some such as Blumenbach rejected racial hierarchies). The biological conceptions of races, elaborated by the scientific racists, shaped the way Europeans and Americans thought of races as well as interracial relations all over the world in the 19th and the first part of the 20th century before being challenged.¹² The ideas of Gobineau and his successors were used to justify much of the racism that existed in the late 19th and the early 20th century, including, most infamously, the racism of Adolf Hitler and the Nazi Party.¹³ The rejection of the biological approach to races was made official in 1950 when, motivated in large part by the horror of the genocide committed by the Nazis, the UNESCO released a statement by leading sociologists and anthropologists (including Lévi-Strauss and Montagu) criticizing the biological conceptions of race.¹⁴ The American civil rights movement of the 1950s and 1960s led to the dismantling of the racist structures that had existed in the United States. Apartheid, South Africa's system of racial separation, was abolished in the early 1990s. Racism means more than simply not liking someone because of his perceived race. Racism leads to racial discrimination, which directly affects the lives of its victims. Racist hate groups, such as the Ku Klux Klan, have targeted blacks, harassing, assaulting, and sometimes killing them; prison and death row statistics suggest racism; lighter-skinned people have better chances of success than those with darker complexions; the darker skinned people do not have the same opportunities as whites; anti-Semitism, or hostility toward Jews, persists and is widespread; the Internet is filled with web sites claiming that Jews control the world's money and that they are trying to take over the world, the same ideas that Hitler used to maintain his control in Germany. The Roma, who were highly persecuted by Hitler, still face racial discrimination in many European countries; in the USA the discrimination against Indians continues to flourish; in Japan, the Ainu and Burakumin, along with Korean immigrants, face constant discrimination; in Indonesia, ethnic Chinese are viewed with suspicion by many ethnic Indonesians and have been subjected to racist attacks¹⁵; anti-Asian and anti-Chinese xenophobia, paranoia (Yellow alert) and racist abuse mount over the outbreak of the new Wuhan coronavirus in China after the global public health emergency was declared; and finally, one of the most gruesome consequences of racism were medical experiments on humans of "lower" race.

12 Machery, Edouard (2014), 2138.

13 Skutsch, Carl (2001), 856.

14 Machery, Edouard (2014), 2138.

15 Skutsch, Carl (2001), 856.

On medical racism

The idea that racial differences might play a role in medical diagnosis and treatment is profoundly disturbing. The racially biased treatment of patients is a grievous violation of medical ethics and a direct threat to the dignity of the profession. Yet, the medical literature has published hundreds of peer-reviewed studies that point to racially motivated decisions by physicians either to deny appropriate care to black patients or to inflict on them extreme procedures that many white patients would be spared.¹⁶ Medical racism is prejudice and discrimination in medicine and the medical/healthcare system based upon perceived race. Racism in medicine can occur in at least four ways:

- First, *on a conceptual level*, it can occur as members of a society learn about races and racism as well as the validity of white privilege. Healthcare providers are a product of their social environment. They learn negative attitudes and beliefs about human biological diversity from a society that may be brought to the work/health setting. They may be unaware of this racism, and it can be subtle or overt.
- Second, *collective racial discrimination*, based on shared cultural beliefs, can result in differential medical treatment and health care. Physicians' perceptions of patients are influenced by gender, socioeconomic status, and race/ethnicity. These perceptions affect physicians' behaviour in medical encounters. Training as a physician, nurse, or other health-care provider does not prepare one to interact with people of other races/ethnicities. Physicians, nurses, and other health-care workers are part of society and are subject to the same biases and prejudices that are found in society.
- Third, experiences with racism in society and the medical setting can result in *stress* that negatively impacts health. Racial discrimination is related to decreased measures of personal life satisfaction, more psychological distress, experiences with racism can impair the cardiovascular system and may lead to higher blood pressures.
- Lastly, *institutional racism* in the medical/healthcare system can affect the quality and quantity of health care for minorities. Institutional racism occurs when one or more of the institutions of a society function to impose more burdens on and give less benefit to members of one racial or ethnic group than another on an ongoing basis. The medical care system is an institution and like other institutions reflects the racial culture of the wider society.¹⁷ Institutional racism is the process by which racial oppression is imposed on subordinate racial groups by dominant racial groups through institutional channels. While individuals carry out single acts of discrimination,

16 Hoberman, John M. (2012). *Black and Blue: The Origins and Consequences of Medical Racism*. Berkeley, Los Angeles, London; University of California Press, 1.

17 Hutchinson, Janis Faye (2008), 292, 293, 294, 296.

societal institutions are the primary settings where patterns of racial discrimination are established and perpetuated toward subordinate peoples. Central to the operation of institutional racism is a racial hierarchy of power. Institutionalized racism tends to be prevalent in countries that have both dominant and subordinate racial groups. Institutional racism takes two major forms: direct and indirect institutionalized discrimination. The former type involves overt actions prescribed by dominant-group organizations that have a discriminatory impact on subordinate racial groups. Institutional racism in one area can have substantial effects in another, which results in a cumulative dynamic.¹⁸ Institutional racism is a subcategory of *structural racism*, which refers to the ways in which historical and contemporary racial inequities in outcomes are perpetuated by social, economic, and political systems, including mutually reinforcing systems of health care, education, housing, employment, the media, and criminal justice. It results in systemic variation in opportunity according to race or ethnic background – for example, in racial differentials in access to health care.¹⁹

II. On medical experimentation

The use of experimentation on human subjects is a necessary method of advancing medical and public health knowledge. However, it has been abused extensively in the context of genocide and crimes against humanity, especially by the Axis Powers during World War II. Experimentation was part of the state-sanctioned behaviour of Nazi doctors within the broader program of extermination of races considered inferior or of targeted political groups. The medical and health personnel involved were charged with having committed war crimes and crimes against humanity during World War II, and many were convicted by a U.S. tribunal set up in tandem with the International Military Tribunal sitting in Nuremberg. Medical experimentation refers to the testing and evaluation of a new drug or procedure on a human person in order to gain generalizable knowledge that can be used for various purposes. In its accepted form, such experimentation is conducted on *willing human subjects* for the purpose of advancing the curative or preventive role of medicine. In its prohibited form—done in connection with genocide or crimes against humanity – it is conducted *without the consent* of the individuals tested and for the purposes that may purport to have a positive value for medical science, such as finding a vaccine against smallpox, or for the misuse of medicine, such as learning how to keep a

18 Lavelle, Kristen M., Feagin, Joe R. (2008). Institutional Racism. *Encyclopedia of Race and Racism*. Volume 2, g–r. Thomson Gale, 180, 181.

19 Pallok, Kristen, De Maio, Fernando, Ansell, David A. (2019). Structural Racism – A 60-Year-Old Black Woman with Breast Cancer, *The New England Journal of Medicine*, 380 (16), April 18, 1491.

prisoner from dying under torture, in order to continue the acts of torture. The trial of the Nazi doctors was, in many ways, the defining moment of standard-setting regarding medical experimentation. The practice is, however, an ancient one, found among physicians in ancient Greece and Rome, the Arab and Ottoman Empires, and especially in European medical practice during the 18th and 19th centuries.²⁰

The controversial gynaecological cases of Lucy, Betsey, Anarcha and other slaves

It did not take long after the first slaves reached the shores of the New World before physicians started using them as a ready source of the material. Beginning in the 1800s, radical surgeries and vaccinations were performed to test medical treatments and verify the safety of new vaccines. Dr James Marion Sims (1813–1883), considered a pioneer in gynaecological surgery, performed numerous operations on slaves to perfect his techniques.²¹ Sims, the father of gynaecology and a president of the American Medical Association (1875–1876), experimented between 1845 and 1849 on slave women in an attempt to find a cure for vaginal fistula. Experimentation on these women was considered acceptable because of their "inhuman" status.²² Numerous modern authors have attacked Sims's medical ethics, arguing that he manipulated the institution of slavery to perform ethically unacceptable human experiments on powerless, nonconsenting African American women. He developed the first consistently successful operation for the cure of vesicovaginal fistula, a catastrophic complication of childbirth in which a hole develops between a woman's bladder and her vagina and leads to constant, unremitting, and uncontrollable urinary incontinence. The fistula victims, a condition for which no other viable therapy existed at that time, have experienced enormous suffering. He operated on black women without the introduction of anaesthesia. He performed his first operation on a slave woman named Lucy. Lucy was operated on without anaesthetics. A seventeen-year-old slave, named Anarcha, with a particularly difficult combination vesicovaginal and rectovaginal fistula, underwent 30 operations before Sims was able to close the holes in her bladder and rectum.²³ Lucy, Betsey and Anarcha were young women from the plantations who had recently delivered their first babies. Neither their deliveries nor

20 Marks, Stephen P. (2005). Medical Experimentation. *Encyclopedia of genocide and crimes against humanity*. Volume Two I–S. Dinah L. Shelton (Ed.), Thomson Gale, 669–670.

21 Golizek, Andrew (2008). Medical Experimentation. *Encyclopedia of Race and Racism*. Volume 2, g–r. Hartwell Moore, John (Ed.), Thomson Gale, 290.

22 Hutchinson, Janis Faye (2008), 294.

23 Wall, Lewis L. (2006). The medical ethics of Dr J Marion Sims: a fresh look at the historical record, *Journal of Medical Ethics*, 32, 346.

the condition of their infants are ever described. In the South, in the 19th-century slave population between the ages of fifteen and forty-four were pregnant every year and were often the object of aggressive sexual demands of their masters. Slave women occasionally suffered great hardship during childbirth. Prolonged labour among black women, for instance, was related to nutritional deficiencies, and it directly led to the appearance of fistulas. Physicians were willing to experiment surgically on slave women before the introduction of anaesthesia. Sims surgically experimented on eleven women between 1846 and 1849. Lucy, Betsey and Anarcha stayed with Sims as his assistants for four years. It is possible that staying with him in the hospital was a better choice than being on the plantation. Since he gave them opium after the operations, it is also possible that they became addicted and therefore stayed with him and accepted the situation.²⁴ Sims's critics make three major claims about his early operations. The first assertion is that it was unethical by any standard' to perform experimental surgical operations on slaves because slaves, by definition, could not have given voluntary informed consent for surgery. This assertion is the hidden presupposition that enslaved women with fistulas did not want surgical care for their condition (vesicovaginal fistula) and that they were therefore coerced into having unwanted (and perhaps, unnecessary) surgery. The second assertion is that Sims's failure to use ether anaesthesia during these operations was racist: that he did not use anaesthesia when performing fistula surgery on black women, but later, after developing his operation and moving to New York to found the Woman's Hospital there, he routinely used anaesthetics when operating on white women who, unlike blacks, were unable to stand the pain involved. The third assertion is that the use of slaves for medical experimentation was unnecessary because substantial advances in medical care were made in the 19th century by Southern physicians who experimented in an ethical manner using white women from whom they obtained "informed consent", a circumstance that modern critics assert did not exist with regard to Sims's operations on these early slave women. However, the examination of primary source material demonstrates that each of these claims about Sims is either unsubstantiated or false. At the time Sims began his efforts to close vesicovaginal fistulas, there was no effective alternative to surgical treatment, and he began his fistula operations on his enslaved patients in late 1845, before the anaesthetic properties of ether were known. Anaesthesia was discovered and publicly demonstrated in Boston on October 16, 1846, nearly one year later. Although the use of anaesthesia spread rapidly, its acceptance was not universal. Sims's accounts from 1855 of these early fistula operations all state quite plainly that he discussed what he proposed to do and obtained consent from the patients themselves before undertaking any operations.

24 Kuhn McGregor, Deborah (1998). *From Midwives to Medicine: The Birth of American Gynecology*. New Brunswick, NJ; Rutgers University Press, 38, 40, 41, 42, 43, 46, 54.

Under Southern law, slaves were the property of others, and Sims could not have legally operated on them without the consent on their owners; however, this cannot be taken as a priori proof that these slaves were unwilling patients. He pursued clinical goal and his patients then and countless thousands of women since, benefited from his success.²⁵

Other cases of medical experimentation (not) involving the principle of informed consent

Among the best-known examples of medical advances made thanks to medical experimentation are Edward Jenner's inoculation of an eight-year-old boy with cowpox against smallpox (1796), Sir James Young Simpson's use of chloroform for anaesthesia (1847), and Louis Pasteur's testing an antidote to rabies on a nine-year-old boy (1885). Although these advances have proved important, the experimentation sometimes took place without adequate attention to acquiring informed consent or reference to previous scientific studies, and testing usually took advantage of vulnerable groups, such as children, orphans, prisoners, and patients with mental illness. One of the first efforts to establish ethical standards for medical experimentation was made by the English physician, Thomas Percival, in 1803. In the book *Medical Ethics; or, a Code of Institutes and Precepts, Adapted to the Professional Conduct of Physicians and Surgeons* he wrote that doctors performing "new methods of chirurgical treatment should be scrupulously and conscientiously governed by sound reason, just analogy, or well authenticated facts and no such trials should be instituted without previous consultation of the physicians or surgeons."²⁶ More directly to the point of human experimentation was the code drafted by an American, William Beaumont, in 1833, requiring voluntary consent of the subject and cessation of the experiment when it causes distress to the subject or when the subject is dissatisfied with it. Beaumont performed physiological experiments of the stomach on wounded, uneducated Alexis St. Martin from 1822–1833 what led to the important discovery that digestion was primarily a chemical process and not a mechanical one. His experiments are described in *Experiments and Observations on the Gastric Juice and the Physiology of Digestion* (1833).²⁷ The French physician Claude Bernard, writing in the middle of the 19th century, defined the basic principle of "never performing on man an experiment which might be harmful to him to any extent, even though the result might be highly advantageous to science, i.e., to the health of others." The principle

25 Wall, Lewis L. (2006), 32, 346, 347, 348, 349.

26 Marks, Stephen P. (2005), 670.

27 Marks, Stephen P. (2005), 670; Helms, Robert (2002). *Guinea Pig Zero: An Anthology of the Journal for Human Research Subjects*. Garrett County Press.

of informed consent evolved as a result of several well-known experiments. During World War I, Walter Reed experimented with mosquitoes as a vector of yellow fever, first on servicemen and then on Spanish workers. His test subjects signed a contract by which they accepted the risk of yellow fever in exchange for \$100 in gold, and twice that amount was paid if they contracted the disease. The ethical problem with Reed's experiment was that prospective test subjects were recruited on the basis of false information. The certainty of non-participants in the experiment contracting yellow fever was exaggerated, and the possible fatal consequences of the experiment were understated. In the early 20th century, a collaborator of Reed, George Sternberg, experimented on children in an orphan asylum, as well as on mental patients and prisoners. Although criticized for it, Hideyo Noguchi and his colleagues tested a drug to diagnose syphilis on uninformed mental patients, patients in public hospitals, and orphans. These examples raised problems of medical ethics, and this concern contributed to the rethinking of rules governing medical experimentation in the mid-20th century. During World War II, the Committee on Medical Research of the Office of Scientific Research and Development – the precursor to the National Institutes of Health—conducted major experimental research using human subjects on diseases such as dysentery, influenza, and especially malaria. Again, mental patients and prisoners were infected to determine their response to antimalarial therapies and flu vaccines. The subjects were usually considered volunteers, but little attention was paid to the nature of their consent. For instance, prisoners were often promised early release, but no one stopped to think of how that promise might induce a prisoner to give consent to the experimentation. The overriding concern was for results, because the tests would directly affect the health of soldiers engaged in the war effort. Hepatitis testing on mentally retarded children at Willowbrook and cancer research, using live cancer cells, on unsuspecting patients at the Brooklyn Jewish Chronic Disease Hospital were also conducted without adequate attention to the consent of the subjects and the ethics of the use of live cancer cells.²⁸

Perhaps the most notorious example in the United States of failure to apply standards of informed consent was the *Tuskegee study*, which the U.S. Public Health Service ran from 1932 to 1972. The test subjects were African Americans with secondary syphilis and were not conscripted during the war and in order to allow the scientific team to continue studying the progression of the disease, were not given penicillin even after its efficacy against the disease was discovered.²⁹ The study involved 623 black male volunteers – 399 with syphilis, and the rest without it. Government officials recruited African American participants in the study by offering “free medical care”

²⁸ Marks, Stephen P. (2005), 670–671.

²⁹ *Ibid.*, 670–671.

to them (for everything except syphilis). They were also given free transportation to the research site, free meals when they arrived and burial insurance. The men recruited were mostly poor sharecroppers from Macon County, Alabama, which had a high rate of syphilis cases. These men had difficult lives, hoeing small plots of land, living in wooden shacks, picking cotton in the season and because of their poverty having a very small chance of seeing a doctor. The men enrolled in the study were never told they had syphilis. Researchers kept this information from them and told the patients that they were being treated for “bad blood”, a local term used to describe several ailments, including syphilis, anaemia, and fatigue. In truth, the 399 syphilitic patients did not receive what they signed up for. They were never given the proper treatment needed to cure their syphilis since the government wanted to study untreated syphilis. Penicillin came into use in 1947, which could cure syphilis. The doctors were also interested in whether the disease affected whites and blacks differently. The doctors and nurses were not there to cure, but to observe the progress of untreated syphilis. When 250 of the men volunteered for military service, they were rejected due to their syphilis. Still, they were denied treatment, causing them to be denied service to their country and benefits from the military. Although initially projected to last 6 months, the study actually went on for 40 years, the entire time the participants assumed that they were being treated. Instead, the government was purposely letting their disease progress for the study. Patients who are untreated sometimes develop no symptoms, and sometimes spontaneously recover; but they can also suffer greatly. Rashes, skin growths, liver deformity, heart damage, paralysis, insanity, and death are all possible outcomes of the untreated disease. The experiment continued in spite of the Henderson Act (1943), a public health law requiring testing and treatment for venereal disease, and despite the World Health Organization’s Declaration of Helsinki (1964), which specified that “informed consent” was needed for experiments involving human beings. When the study stopped in 1972, 28 men had died of syphilis, 100 died of related complications, at least 40 wives had been infected and 19 children were born with congenital syphilis. The subjects were never given the choice of quitting the study, even when new, highly effective treatment became widely used. When the experiment was brought to the attention of the media in 1972, the government ended their experiment, and for the first time provided the men with effective medical treatment for syphilis. After Tuskegee, major changes in federal rules governing medical research were established, including *written informed consent* and the creation of *institutional review boards* to oversee human subject research. The study also created another legacy – it became the metaphor for the distrust of scientific research, the risks of government provision of medical care, and the exploitation of poor patients. In 1997, then-President Bill Clinton formally

apologized for the U.S. government wrongdoing during the experimentation.³⁰ There is no doubt that in the 19th and early 20th century much of the medical community was convinced that black responded to diseases differently than whites, that it is one of the many differences in races – different in these cases meant inferior. Over time the focus from race shifted to class differences. In the 1930s, doctors had no “official” code of ethics, their moral and ethics were based on peer review of other doctors; and, licenced physicians seldom passed judgements on each other. The doctors involved in the Tuskegee study used a black nurse to persuade the families of the dead victims of an experiment to allow the performing of autopsies because the families trusted her even if they did not trust doctors. All involved in the study violated the trust, repeatedly telling the victims that they were helping them to get better when, in fact, they were observing the deterioration of their health.³¹

Another case involves a black woman *Henrietta Lacks*, born Loretta Pleasant (1920–1951) from Roanoke, Virginia who died of cervical cancer and who became the source of cells that form the *HeLa* line, used extensively in medical research since the 1950s. Cells were taken from her body without her knowledge. Her case has sparked legal and ethical debates over the rights of an individual to his or her genetic material and tissue. Before her fifth pregnancy, Henrietta sensed a knot inside her. After pains and bleeding in her abdomen in January 1951, several months after giving birth, she finally went to Johns Hopkins Hospital in Baltimore, where she was diagnosed with a fatal form of cervical cancer that had been undetected by doctors both at the birth of her son in 1950 and at a follow-up examination. She had radiation treatment, and doctors removed two cervical samples from her without her knowledge. She died at Johns Hopkins in October the same year when she was 31 years old. The cells from her tumour were sent to the laboratory where one researcher noticed an unusual quality in the cells. Unlike most cells, which survived only a few days, her cells were far more durable. He isolated and multiplied a specific cell, creating a cell line. He named the resulting sample HeLa, derived from the name *Henrietta Lacks*. The HeLa strain revolutionized medical research. They were used to develop the polio vaccine, in researches for Parkinson disease, leukaemia, hormones, steroids and vitamins, gene mapping, in vitro fertilization, what sparked mass interest in the cells. As demand grew, scientists cloned the cells in 1955. Since that time, over ten thousand patents involving HeLa cells have been registered. Researchers have used the cells to study disease and to test human sensitivity to new products and substances. The contribution to advances in biomedical research was made possible by

30 *The search for the legacy of the USPHS syphilis study at Tuskegee* (2011). Katz, Ralph V., Warren, Rueben C. (Eds.), Lexington Books.

31 Jones, James H. (1993). *Bad Blood. The Tuskegee Syphilis Experiment*. New York: Free Press, 17, 95, 96, 148, 152, 219.

Henrietta Lacks and HeLa cells. At the time the cells were taken from her tissue, the practice of obtaining informed consent from cell or tissue donors was essentially unknown among academic medical centres. There was no established practice of seeking permission to take tissue for scientific research purposes. The laboratory that received her cells obtained such cells from any patient diagnosed with cervical cancer as a way to learn more about a serious disease that took the lives of so many. Johns Hopkins Hospital never patented HeLa cells, nor did it sell them commercially or benefit in a direct financial way. Today, research-based medical centres consistently obtain consent from those asked to donate tissue or cells for scientific research. The Lacks family learned about the HeLa cells in the 1970s. In 1973, a scientist contacted family members, seeking blood samples and other genetic materials, but inquiries from the family regarding the use of HeLa cells, and publications that included their own genetic information, were largely ignored. The case gained new visibility in 1998 when the BBC screened an award-winning documentary on Lacks and HeLa. In 2010 Rebecca Skloot wrote a popular book *The Immortal Life of Henrietta Lacks*. Organizations that have profited from HeLa have since publicly recognized Henrietta Lacks' contributions to research. The HeLa case has raised questions about the legality of using genetic materials without permission. Neither Lacks nor her family granted permission to harvest her cells, which were then cloned and sold. In 2013, German researchers published the genome of a strain of HeLa cells without permission from the Lacks family. The Lacks family has had limited success in gaining control of the HeLa strain. In August 2013, an agreement between the family and the National Institutes of Health granted the family acknowledgement in scientific papers and some oversight of the Lacks genome.³² HeLa ethical issues are intertwined with regulations from the time before anyone could imagine what we can learn from a bit of DNA. They were based on the standpoint that if samples are “anonymized”, there is no need to get consent before using them in research. Here ethical question again tackles the informed consent – how much information is enough? The other important issue, in this case, is also making a profit from the development or sale of human genetic material. What body parts can be sold, and who legally owns them? What role does progeny have? Henrietta's children and grandchildren did not know for two decades that any cells were taken from her and what has happened to them, not to mention that some of them had bitter lives and were living on the edge of poverty.

Knowledge of the racial dimension in medical history curbs the temptation to excuse racially biased medicine. It was not until Henry Beecher published his groundbreaking article, “Ethics and Clinical Research,” in 1966 that the laxity of standards

³² *Henrietta Lacks*, available at: <https://www.biography.com/scientist/henrietta-lacks> (accessed February 3, 2020); Etheredge, Laura. *Henrietta Lacks*, available at: <https://www.britannica.com/biography/Henrietta-Lacks> (accessed February 3, 2020); Skloot, Rebecca (2010). *The Immortal Life of Henrietta Lacks*. Crown Publishing.

for experimentation in medical schools, hospitals, and government institutions was considered urgent enough for clear rules and monitoring procedures to be established. By far, the most significant precedent for the dangers of unrestricted and barbaric medical experimentation was the one set by the Nazi and Japanese doctors before and during World War II. Japanese physicians conducted germ warfare experiments in the early 1930s under the direction of Lieutenant-General Shiro Ishii. Some 20,000 Japanese professionals were involved in experiments on humans and participated in massive germ warfare attacks against Chinese and Korean civilians and U.S. prisoners of war. An estimated 400,000 Chinese died of cholera as a result of these attacks, and the final death toll of Japan's medical-biological war crimes has been estimated at 580,000. Unit 731, the most notorious secret military medical unit of the Imperial Japanese Army, was a facility of 150 buildings on six square kilometres. There, a number of experiments were carried out on human subjects, including vivisections, grenade tests, frostbite experiments, and a bacilli bomb developed for use as a defoliant. The U.S. government did not prosecute the Japanese perpetrators for these acts as they did in the case of the Nazi doctors. Instead, the crimes were left unprosecuted, in exchange for access to test results and documents³³.

Selected experiments carried out by Nazi physicians during World War II

At the end of World War II, twelve experiments were singled out for prosecution as war crimes. Extensive evidence was presented for each of them during the trial of the Nazi physicians.

High-altitude (or low pressure) experiments

In Auschwitz, the concentration camp victims were subjects to be dispensed with at any time and at the whim of those in authority. The physician Dr Sigmund Racher, who conducted one of the most notorious experiments, the effects of high altitude on human survival, asks in a letter addressed to Heinrich Himmler, the second most powerful man in the Third Reich, to dispense with "two or three professional criminals" to be used in his experiments. This is because Racher writes "such experiments on human beings are very dangerous and nobody is volunteering." Dr Rudolf Brandt, on behalf of Himmler, replies: "I can inform you that prisoners will, of course, be gladly made available for the high flight researches. I want to use the

³³ Marks, Stephen P. (2005), 671.

opportunity to extend to you my cordial wishes on the birth of your son”.³⁴ Inmates of the Dachau concentration camp in 1942 were locked in an airtight pressure chamber, and the pressure was altered to simulate atmospheric conditions at very high altitude without oxygen. In the words of the official report on this experiment, performed on a 37-year-old Jew: After 4 minutes the experimental subject began to perspire, and wiggle his head; after five minutes cramps occurred; between 6 and 10 minutes breathing increased in speed and the experimental subject became unconscious; from 11 to 30 minutes breathing slowed down to three breathes per minutes, finally stopping altogether. Severest cyanosis developed in between and foam appeared at the mouth. About one-half hour after breathing had stopped, dissection was started. The report then provides a detailed description of the autopsy.³⁵

Freezing experiments

Between August, 1942 and May, 1943 male prisoners of the Dachau concentration camp were forced into an ice water bath as part of a medical research protocol on hypothermia.³⁶ Most of the immersion hypothermia and rewarming experiments were conducted at Dachau along with some initial cold-air studies. Also, some cold-air experiments were made at Auschwitz, since the air temperature was colder there than at Dachau. The number of victims involved in the cold-water experiments is not clear, it is estimated that either 130 experiments were performed and 280–300 subjects were involved³⁷ or 300 men were cooled during 400 experiments indicating that many subjects were used more than once. Approximately 90 victims died during the experiments.³⁸ The victims were forced to stand naked in freezing weather for nine to fourteen hours, or in a tank of ice water for three hours. The official Nazi report notes, “the experimental subjects died invariably, despite all attempts at resuscitation.”³⁹ Pain from contact with ice-cold water is excruciating and must have lasted until consciousness was lost. One witness knew of only two of these men who

34 Rapa, Mark Josef (2020). The Nazi experiments and data. *The Malta Independent On-Line*, 30 January, available at <https://www.independent.com.mt/articles/2020-01-30/blogs-opinions/The-Nazi-experiments-and-data-6736219060?fbclid=IwAR1KZdBi-DWrCk8U4MQiD-cOJITD7THxK07Qc0jS9BLQZZLzWU8SHCvU278> (accessed 1 February 2020).

35 Marks, Stephen P. (2005), 671.

36 Berger, Robert L. (1992). Nazi Science. Comments on the Validation of the Dachau Human Hypothermia Experiments. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 109.

37 Pozos, Robert S. (1992). Scientific Inquiry and Ethics. The Dachau Data. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 99.

38 Berger, Robert L. (1992), 110.

39 Caplan, Arthur L. (2007). The Ethics of Evil: The Challenge and the Lessons of Nazi Medical Experiments. *Dark medicine: rationalizing unethical medical research*. LaFleur, William R., Böhme, Gernot, Shimazono, Susumu (Eds.). Indiana University Press, 68.

survived the war and testified that both finished as “mental cases”. The German physician-investigators maintained that the project was designed to find an effective treatment (rewarming) for Air Force (*Luftwaffe*) crews downed into the cold waters of the North Sea and to save them from death through hypothermia. The doctors also claimed that their objective was accomplished.⁴⁰ The university physiologists worked under the supervision of SS physician Sigmund Rascher, who administered Dachau. He was a personal favourite of Heinrich Himmler, chief of the SS. Subjects were selected from among camp inmates with an eye toward their race, health, and age and then were fed an improved diet to make them more suitable subjects. After a few weeks, the men were brought to a special unit in the camp where a vat had been built containing ice and freezing water. The men were immersed until they became unconscious. Vital signs of those thus exposed were monitored and recorded. Various techniques were used to try and revive those who did not die. Those who did die were autopsied on the spot. In the second set of experiments, men were kept standing outside at night while freezing cold water was periodically poured over them. Again, vital signs and temperatures were monitored. The suffering of those subjected to these tortures was so great that some of those involved in carrying out the research did not follow their orders. Conditions outdoors varied a great deal, and the subjects involved were in far worse physical condition than those who had been subjected to the first series of experiments. Both sets of experiments were cruel, inhumane, and immoral. About one-quarter of the subjects died.⁴¹ One man who had survived the hypothermia experiments that involved prolonged submersion in tanks of freezing water and had been sent to Dachau because of his political beliefs said that the researchers told him that if he survived the hypothermia experiments and then the decompression experiments, he might be freed. He was not. He said no prisoners were.⁴² The majority of the experiments were performed by Rascher alone. Thus, responsibility for the final product rests with him. Rascher’s credibility is severely compromised by a consistent pattern of fraud and deception in his other scientific efforts and his personal affairs. His integrity was eventually questioned even by his Nazi mentors. He was arrested in 1944 and charged with a variety of crimes, including scientific fraud. Approximately one year after his imprisonment, Rascher was executed, presumably on Himmler’s orders.⁴³ The German armed forces used the findings in the design of survival suits for soldiers and in developing resuscitation policies for those exposed to cold temperatures, British air-sea rescue experts used

40 Berger, Robert L. (1992), 109–110.

41 Caplan, Arthur L. (1992). How Did Medicine Go So Wrong? *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 67–68.

42 Caplan, Arthur L. (2007), 68.

43 Berger, Robert L. (1992), 112.

the Nazi data to modify rescue techniques for those exposed to cold water; Nazi data have been used by many scientists from many nations.⁴⁴

Forced sterilisation experiments

In medical terms, sterilisation is a surgical intervention which permanently removes an individual's ability to reproduce. In addition to the purpose of contraception, sterilisation can also be performed for health-related reasons when reproductive organs have been damaged. Sterilisation is never a life-saving operation that needs to be performed on an emergency basis and without full and informed consent. Sterilisation should be performed in accordance with the principle of autonomy, expressed through full, free and informed decision-making. The principle of autonomy requires that any counselling, advice or information given by health-care providers or other support staff or family members should be non-directive, enabling individuals to make decisions that are best for themselves, with the knowledge that sterilisation is a permanent procedure and that other, non-permanent methods of fertility control are available. Sterilisation for prevention of future pregnancy cannot be justified on the grounds of a medical emergency, which would permit departure from the general principle of informed consent and that even if a future pregnancy might endanger a person's life or health, there are alternative contraceptive methods to ensure the individual concerned does not become pregnant immediately, and the individual concerned must be given the time and information needed to make an informed choice about sterilisation.⁴⁵

Involuntary sterilisations as a method of population control were practised at the beginning of the 20th century when the science and social movement of eugenics reached its highest popularity. Several countries, among them Germany, Austria, Sweden, Switzerland, Norway, Peru, Bolivia, the USA, Puerto Rico, Australia, and Japan adopted laws promoting coercive sterilisation as a method of improving the genetic constitution of their populations. Forced sterilisation in the 20th and early 21st centuries were often based on the ethnicity or the disability of the victims but has also targeted unmarried mothers, pregnant women who have sought to terminate pregnancies, and the poor. The most prominent involuntary sterilisation policies in Europe were carried out in Austria, the Czech Republic, Denmark, Finland, France,

44 Caplan, Arthur L. (1992), 70.

45 *Female contraceptive sterilization* (2011), available at: http://www.wunrn.org/news/2011/06_11/06_27/062711_female.htm (accessed January 31, 2020); *Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF, WHO* (2014). World Health Organization, available at: http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1 (accessed January 31, 2020).

Germany, Norway, Slovakia, Sweden, and Switzerland. Of those countries, Austria, Germany, Sweden, Norway and Switzerland have assumed responsibility for those policies and put in place special remedies for victims. So have Peru and the U.S. states of North Carolina and Virginia.⁴⁶

The atmosphere of racism and racial hygiene reached its peak in 1930s Germany, with the eugenics programmes from moderates seeking birth control to wanting to eliminate the unfit from the human population. Adolf Hitler assumed that many in the West shared his philosophy that only healthy individuals reproduce. In the beginning, it was simply a matter of sterilisation; the disabled, the mentally ill, and those with genetic disorders were targeted. However, soon euthanasia was added to eliminate anyone who placed an undue burden on society. The final step was human experimentation, in which individuals or races thought inferior were used in medical research for the benefit of superior races.⁴⁷ On July 14, 1933, the Nazi government passed the Law for the Prevention of Genetically Diseased Offspring, or Sterilisation Law, allowing the forcible sterilisation of anyone suffering from genetically determined illnesses, including feeble-mindedness, schizophrenia, manic depressive insanity, genetic epilepsy, Huntington's chorea, genetic blindness, deafness, or severe alcoholism. Doctors were required to register every case of genetic illness known to them; physicians could be fined 150 RM for failing to register any genetic defective. Estimates of the total number of people sterilised in Germany by 1939 range from 350,000 to 400,000. In some areas, more than 1% of the total population was sterilised. As a consequence of the law, sterilisation research and engineering rapidly became one of the largest medical industries. Medical supply companies designed sterilisation equipment; medical students wrote more than 180 doctoral theses exploring the criteria, methods, and consequences of sterilisation. There were obvious incentives for developing more rapid sterilisation techniques, especially for women.⁴⁸

The experiments, conducted on victims in Auschwitz, Ravensbrück, and other camps, were part of Nazi planning for the genocide by the most efficient, scientific, and least conspicuous methods. The aim was to eliminate Russians, Poles, Gypsies, Jews, and other undesirable populations by using medicinal rather than surgical sterilisation, primarily through injection of *caladium sequinum* and other substances. In addition, gland transplantation was performed on fourteen inmates of Buchenwald, two of whom died. Others were subjected to sterilisation by X-rays and castration. The aim

46 *Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF, WHO* (2014), 12.

47 Goliszek, Andrew (2008), 291.

48 Proctor, Robert N. (1992). Nazi Biomedical Policies. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 29–30.

was to prevent reproduction among Jews who were preserved from extermination in order to perform labour.⁴⁹ The medical blocks of concentration camps kept prisoners for special medical procedures. Some blocks were used for mass sterilisations, where caustic agents were injected into the uterus to see how much they would obstruct the oviducts. Virtually every medical block was manned by SS doctors who viewed their subjects as less than human and justified their experiments in the name of improving the lives of German citizens. The atrocities committed were a culmination of a eugenics movement that crossed the line from birth control to mass murder.⁵⁰

Thirty states in the United States passed eugenics laws between 1907 and 1931. By the end of World War II, it was estimated that 40,000 sterilisations had taken place, mostly on poor white women. Because of racial segregation, it was not deemed necessary to sterilise black people at this time. This situation changed, because between 1949 and 1960, for example, of the 104 surgical sterilisations performed in South Carolina mental hospitals, all but two were performed on blacks. All these sterilisations were done on women. These federally funded practices were prevalent in Alabama and North Carolina, also in the 1970s.⁵¹

Mass sterilisation, an outgrowth of the earlier eugenics movement, was common throughout the 1960s and 1970s. In Puerto Rico, as much as 35 percent of the female population was sterilised during the 1960s, ostensibly as a way to moderate growth and maintain economic development. Similar programs were started at the same time in most Third World countries. In the United States, family planning and abortion clinics greatly expanded in black and Hispanic communities, with some women being refused abortions or welfare benefits if they did not consent to sterilisation. The 1990s public health officials encouraged a disproportionate number of African-American women to have themselves and their teenage daughters sterilised as a means of controlling population growth among select minorities.⁵² By 1972 as many as 42 percent of all American Indian women of childbearing age had, by that point, been sterilised without their consent.⁵³ In a 1970s more than 25,000 Native American women were sterilised, many without their knowledge or permission. In all these cases, race played a key role in determining who would be sterilised.⁵⁴ From

49 Marks, Stephen P. (2005), 672.

50 Goliszek, Andrew (2008), 291.

51 Dhruvarajan, Vanaja (2008). Forced sterilizations. *Encyclopedia of Race and Racism*. Vol. 1, a–f. John Hartwell Moore (Ed.). Thomson Gale, 484.

52 Goliszek, Andrew (2008), 292.

53 Jaimes-Guerrero, M. A. (2008). Forced Sterilization of Native Americans. *Encyclopedia of Race and Racism*. Vol. 1, a–f. John Hartwell Moore (Ed.). Thomson Gale, 487.

54 Goliszek, Andrew (2008), 292.

1973 to 1976, for example, 3,406 American Indian women were sterilised, many of whom were under twenty-one years old.⁵⁵

These abuses were carried on through experimentation with birth control methods, such as Depo-Provera and Norplant, which targeted Native American women and other women of colour communities. There is also evidence that indigenous peoples of the Americas, and elsewhere, are being targeted for genetic engineering, particularly in the harvesting of their DNA genomes by geneticists who are in collaboration with corporate pharmaceutical interests. The indigenous women targeted are especially coveted human subjects in the genome research of ancient human origins.⁵⁶

For many decades, disdain towards American Indians as a people was pervasive among health professionals and social workers, and the eugenics boards were quick to characterise women of Indian origin as mentally defective, and therefore as unfit to reproduce. Sterilisation abuse is found to be still going on as late as the 1990s. Paternalistic policies toward American Indians allow the federal government to make decisions on their behalf without their full consent or participation. Sterilisation abuse was going on for quite some time, but they were investigated only since the 1970s.⁵⁷

In the period between 1996 and 2000 at least 200,000 sterilisations took place in Peru. Poor and often illiterate women from the Quechua and Aymara indigenous ethnic groups were the majority of the victims. Quinacrine, a drug that sterilises women permanently, was planted in the uteri of more than 100,000 women through the initiative of two U.S. doctors without testing for their side effects. The doctors claimed that they were doing their country a social service by addressing the epidemic of population explosion in the Third World.⁵⁸

Involuntary sterilisations are a flagrant violation of human rights, human dignity, and of the physical and mental integrity of the human being. Yet, female sterilisation was state policy in Czechoslovakia until 1993 when the Sterilisations Directive was abolished. Moreover, the ERRC report documents that the practice of sterilising Romani women and women with disabilities against their will continued throughout the 1990s and 2000s, with the last known cases documented in 2007 when the Czech Republic was already a Member State of the European Union. Romani women were sterilised without their knowledge or consent. These included manipulation of consent forms and other medical documentation and their signatures forged;

55 Dhruvarajan, Vanaja (2008), 484.

56 Jaimes-Guerrero, M. A. (2008), 487.

57 Dhruvarajan, Vanaja (2008), 484.

58 Dhruvarajan, Vanaja (2008), 486.

procedures were often performed at the same time as caesarean sections, or they were presented with consent forms during labour or delivery. Some Romani women were threatened that their children would be taken away from them, or their social benefits would be withdrawn if they did not accept sterilisation. In some cases, doctors falsely presented sterilisation as a necessary life-saving intervention.⁵⁹

Evidence exists, including by governmental admission and apology, of a long history of forced and otherwise non-consensual sterilisations of women, including Roma women in Europe and women with disabilities. Reports have documented the coerced sterilisation of women living with HIV/AIDS in Africa and Latin America. Fears remain that ethnic and racial minority, HIV-positive, low-income and drug-using women, women with disabilities and other vulnerable women around the world, are still being sterilised without their own freely-given, adequately informed consent.⁶⁰

Experiments on twins

There was an interest among Nazi doctors to discover the secret of multiple births. If the Nazi scientists could acquire this knowledge, the Aryan *Übermensch* could be multiplied at double the natural rate and world conquest would be more imminent. Doctor Josef Mengele, Chief Medical Officer of Auschwitz-Birkenau Concentration Camp, prided himself on his research on twins. The twins were usually children.⁶¹ In 1939, Interior Minister Wilhelm Frick ordered all twins born in the Reich to be registered with Public Health Offices for purposes of genetic research.⁶²

More than 1,500 sets of twins were used in Auschwitz in Mengele's *in vivo* experiments performed on live human beings between 1943 and 1945.⁶³ The procedures included blood transfusions between twin pairs – he wanted to learn how much blood they could lose and still survive, exposure to X-rays, extensive anthropometric measurement, and injection of one twin with a lethal substance (e.g., typhus) for later comparison with the cotwin. Survival victims described the physically cruel

59 Matache, Magda (2016). Coercive and Cruel: Forced Sterilisation of Romani Women [Blog]. *The Health and Human Rights Journal*, December 7, available at: <https://www.hhrjournal.org/2016/12/coercive-and-cruel-forced-sterilisation-of-romani-women/> (accessed January 31, 2020).

60 Female contraceptive sterilisation (2011), available at: http://www.wunrn.org/news/2011/06_11/06_27/062711_female.htm (accessed January 31, 2020).

61 Seiler Vigorito, Sara (1992). A Profile of Nazi Medicine: The Nazi Doctor-His Methods and Goals. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 10.

62 Proctor, Robert N (1992), 28.

63 Mozes Kor, Eva (1992). Nazi Experiments as Viewed by a Survivor of Mengele's Experiments. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 4; Segal, Nancy L. (1992). Twin Research at Auschwitz-Birkenau: Implications for the Use of Nazi Data Today. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 281, 286.

and scientifically senseless nature of the experiments: young, opposite-sex twins, one of whom was hunchbacked, were removed from the barracks. When these children returned, they had been stitched together back-to-back and were in terrible pain. Adult monozygotic female twins had learned that they were to be impregnated by monozygotic male twins to study the transmission of twinning. The liberation of Auschwitz, fortunately, prevented this experiment from taking place.⁶⁴ Mengele killed children with phenol shots to the heart and then performed autopsies on their bodies, comparing their diseased organs with the organs of their twins.⁶⁵ In Auschwitz, twins were chosen to remain alive by Dr Josef Mengele, who selected them for so-called medical experimentation. Those picked by Mengele were usually taken to a special hut, where they received better nourishment than the rest of the inmates. Ultimately, however, most of them suffered miserable deaths from infection and other complications of the gruesome experiments. German officers at the camps also sometimes chose boys as their personal servants. Such children were often sexually abused, and in camp parlance were called “*Piepels*,” meaning personal boys.⁶⁶ Among the many atrocities, Mengele was killing Romani twins to study comparative eye colouration.⁶⁷ Once he killed 14 Romani twins in one night by injecting chloroform in their heart and sent their eyes and other organs to the Kaiser Wilhelm Institute in Berlin to his professor Otmar Von Verschuer who introduced him to twin research with its racial implications.⁶⁸ Mengele’s lab experiments would last from 8–10 hours three times a week,⁶⁹ and were performed through coercive means upon helpless prisoners. They were part of an extensive system of pseudo-investigation conducted by Nazi medical practitioners who had violated the Hippocratic Oath.⁷⁰

In the concentration camps, medical experiments were performed on inmates until the end of the war. Besides the above described (selected) experiments Nazi doctors also tested communicable diseases on inmates, such as: typhus, yellow fever, smallpox, paratyphoid A and B, cholera, and diphtheria in Buchenwald and Natzweiler; they performed epidemic jaundice experiments on Jews in Sachsenhausen and Natzweiler concentration camps and malaria experiments in Dachau. They also performed experiments with drugs, muscle and nerve regeneration, and bone transplantation

64 Segal, Nancy L. (1992), 284, 286.

65 Mozes Kor, Eva (1992), 4, 5.

66 Keren, Nili, (2001). Children, *The Holocaust Encyclopedia*. Laqueur, Walter, Tydor Baumel, Judith (Eds.). New Haven, London: Yale University Press, 117.

67 Fisher, Barry A (2001). Roma (“Gypsies”). *The Human Rights Encyclopedia*, Volume Three. Lewis, James R., Skutsch, Carl (Eds.). Sharpe Reference, 887.

68 Annas, George J. (1992). The Human Genome Project in Perspective: Confronting Our Past to Protect Our Future. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 311–312.

69 Mozes Kor, Eva (1992), 4, 5.

70 Segal, Nancy L. (1992), 287.

on women in Ravensbrück with inflicting wounds and introducing bacterial cultures to cause severe infections. Experiments in Sachsenhausen and Natzweiler with bio-chemical substances, such as injected, ingested or inhaled poisonous mustard gas caused intense pain and the swelling. In other experiments on Russian inmates, doctors observed the victims' reactions to the poison up to the point of death, or, like in Buchenwald, inmates were burned with phosphorous material in bomb experiments. In Dachau, Roma inmates were used in seawater experiments in which they were forced to drink seawater to the point of delirium, convulsions and death. Anthropological experiments on Jewish included, besides anthropological measurements and photography, the collection of their skulls, which were taken by beheading while they were still alive. The collection of skulls was meant to represent the prototype of the repulsive but characteristic subhuman. Murders, tortures, and other war atrocities committed in the name of medical science were only partially prosecuted after the war, even if the doctors' intention was not to rescue or to cure, but to destroy and kill.⁷¹

III. Discussion and conclusion: Between racial profiling in medicine, using data obtained by crimes, torture and consent and selling race

The long evidence of examples of shocking medical experimentation in history raises important legal, medical, and ethical questions. The answers to these questions would give an opportunity for social justice for all, but especially for vulnerable demographic groups in the future. Unethical medical research from the past should be the lesson for the future and not the ground for its rationalisation. The motto from the Hippocratic Oath "To do no harm," was many times forgotten or exchanged for aims that had nothing to do with humane treatment in medicine – like brutal exterminatory, racist intentions, non-existent legislation or regulations, in the name of development of medicine, or even because of scientific competition. Deviations from medical professional ethics were done in peace as well as wartime conditions. None of these explanations should be accepted as sufficient, correct, and ethical. There were plenty of attempts to forget, to repress or to minimize non-ethical medical experimentation from the past; however, these experiments should not be unforgotten.

The main question regarding the results of unethical medical experimentation is, whether we should or should not use the data obtained in the experiments. Can

71 Marks, Stephen P. (2005), 671, 672, 673.

anything at all justify the pain, suffering and deaths of so many people? These debates have continued at least since the end of World War II. The fact is that the results of former experiments *are* used, as it was shown in the paper and that modern medicine is built upon them.

Even today's medicine considers reasonable to stratify health statistics by race, as long as employment, housing, income, education, or health care is stratified by race; but to use race as a proxy for a response to medical treatment is questionable because members of the same race often differ as much in their response to medical treatment as members of different races do, and racial profiling in medicine helps to sustain a harmful racial ideology.⁷² Illnesses such as cystic fibrosis or sickle-cell anaemia may be more prevalent in some groups that can be identified phenotypically, for example, by skin colour. However, a great many black and white individuals carry genes from a wide range of so-called racial groups. The key reason for differences in health between white and non-white is the relative lack of access to primary medical care, unemployment, poverty and other inequalities of people of colour.⁷³ The question at the population level is not whether race should be used as a population variable in health research but which racial categories should be used and how members of a population should be assigned to them. The question at the individual level is whether race should matter at all, given the variation within each race in the response of patients to medical treatments.⁷⁴

Today, few people outside the Neo-Nazi circles or right-wing groups would admit that they are racists. However, there is a global trend and lucrative cosmetic industry in collaboration with aesthetic medicine and dermatology that promotes skin-whitening among black people. Here, the dynamics of race, class and gender intersect and try again to reinforce one race on another. Skin-whitening is a symbolic investment in whiteness by non-white people that entails a conscious consumption of skin-lightening products for the aim of achieving corporal transformation by reducing or preventing the presence of melanin, the pigment that is responsible for skin colour. Skin-whitening is one of the fastest developing sectors of the cosmetics industry that targets primarily African, Asian and North American markets. The trend of skin-whitening goes back to 19th- and 20th-century United States history, when both African Americans and immigrant women from Eastern and Southern European countries often used skin whiteners, hair straighteners, and elective surgeries to soften their ethnic and racially distinct features in the hope of mimicking the idealised Anglo Saxon features of the “native” women, determined to achieve a

72 Root, Michael (2017), 463.

73 Rattansi, Ali (2007). *Racism: A Very Short Introduction*. Oxford University Press, 94, 141.

74 Root, Michael (2017), 463.

“proper white American appearance”. The imperatives of colourism, racism, ageism and sexism are the driving forces behind transnational corporate slogans that fair skin is healthier and prettier to women and men, regardless of ethnicity or racial difference.⁷⁵ Obviously, today racism exists in many forms and makes a profit under the neo-liberal capitalist order. “Racism sells” is the last fact in the history of racial medicine.

Bibliography

- Annas, George J. (1992). The Human Genome Project in Perspective: Confronting Our Past to Protect Our Future. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 301–320.
- Berger, Robert L. (1992). Nazi Science. Comments on the Validation of the Dachau Human Hypothenia Experiments. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 109–134.
- Caplan, Arthur L. (1992). How Did Medicine Go So Wrong? *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 53–94.
- Caplan, Arthur L. (2007). The Ethics of Evil: The Challenge and the Lessons of Nazi Medical Experiments. *Dark medicine: rationalizing unethical medical research*. LaFleur, William R., Böhme, Gernot, Shimazono, Susumu (Eds.). Indiana University Press, 63–72.
- Dhruvarajan, Vanaja (2008). Forced sterilizations. *Encyclopedia of Race and Racism*. Vol. 1, a–f. John Hartwell Moore (Ed.). Thomson Gale, 483–486.
- Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF, WHO* (2014). World Health Organization, available at: http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1 (accessed January 31, 2020).
- Etheredge, Laura. *Henrietta Lacks*, available at: <https://www.britannica.com/biography/Henrietta-Lacks> (accessed February 3, 2020).
- Etheredge, Laura. *Henrietta Lacks*, available at: <https://www.britannica.com/biography/Henrietta-Lacks> (accessed February 3, 2020).
- Female contraceptive sterilization* (2011), available at: http://www.wunrn.org/news/2011/06_11/06_27/062711_female.htm (accessed January 31, 2020).
- Female contraceptive sterilization* (2011), available at: http://www.wunrn.org/news/2011/06_11/06_27/062711_female.htm (accessed January 31, 2020);
- Fisher, Barry A (2001). Roma (“Gypsies”). *The Human Rights Encyclopedia*, Volume Three. Lewis, James R., Skutsch, Carl (Eds.). Sharpe Reference, 876–884.
- Goliszek, Andrew (2008). Medical Experimentation. *Encyclopedia of Race and Racism*. Volume 2, g–r. Hartwell Moore, John (Ed.), Thomson Gale, 290–292.
- Helms, Robert (2002). *Guinea Pig Zero: An Anthology of the Journal for Human Research Subjects*. Garrett County Press, available at: <https://www.guineapigzero.com/> (accessed January 31, 2020).
- Henrietta Lacks*, available at: <https://www.biography.com/scientist/henrietta-lacks> (accessed February 3, 2020).
- Hoberman, John M. (2012). *Black and Blue: The Origins and Consequences of Medical Racism*. Berkeley, Los Angeles, London; University of California Press.

⁷⁵ Mire, Amina (2020). *Wellness in Whiteness. Biomedicalization and the Promotion of Whiteness and Youth among Women*. Routledge, 55, 56, 57, 58.

- Hutchinson, Janis Faye (2008). *Medical Racism. Encyclopedia of Race and Racism*. Volume 2, g–r. Hartwell Moore, John (Ed.), Thomson Gale, 290–298.
- Jaimes-Guerrero, M. A. (2008). Forced Sterilization of Native Americans. *Encyclopedia of Race and Racism*. Vol. 1, a–f. John Hartwell Moore (Ed.). Thomson Gale, 487–488.
- Jones, James H. (1993). *Bad Blood. The Tuskegee Syphilis Experiment*. New York: Free Press.
- Keren, Nili, (2001). Children, *The Holocaust Encyclopedia*. Laqueur, Walter, Tydor Baumel, Judith (Eds.). New Haven, London; Yale University Press, 115–119.
- Kuhn McGregor, Deborah (1998). *From Midwives to Medicine: The Birth of American Gynecology*. New Brunswick, NJ; Rutgers University Press.
- Lavelle, Kristen M., Feagin, Joe R. (2008). Institutional Racism. *Encyclopedia of Race and Racism*. Volume 2, g–r. Thomson Gale, 180–183.
- Machery, Edouard (2014). Social versus Biological Conceptions of Race. *The Wiley Blackwell encyclopedia of health, illness, behavior, and society*. (Eds.) William C. Cockerham, Robert Dingwall, and Stella R. Quah. John Wiley & Sons, Ltd., 2136–2143.
- Machery, Edouard, Faucher, Luc (2004). Why do we Think Racially? A Critical Journey in Culture and Evolution. H. Cohen C. Lefebvre. *Categorization in Cognitive Science*, Elsevier, 2. https://jeannicod.ccsd.cnrs.fr/ijn_00000531/document, accessed, January 28, 2020.
- Maier, Pauline (1998), *American Scripture: Making the Declaration of Independence*. Vintage Books.
- Marks, Stephen P. (2005). Medical Experimentation. *Encyclopedia of genocide and crimes against humanity*. Volume Two I–S. Dinah L. Shelton (Ed.), Thomson Gale, 669–675.
- Matache, Magda (2016). Coercive and Cruel: Forced Sterilisation of Romani Women [Blog]. *The Health and Human Rights Journal*, December 7, available at: <https://www.hhrjournal.org/2016/12/coercive-and-cruel-forced-sterilisation-of-romani-women/> (accessed January 31, 2020).
- Mire, Amina (2020). *Wellness in Whiteness. Biomedicalization and the Promotion of Whiteness and Youth among Women*. Routledge.
- Mozes Kor, Eva (1992). Nazi Experiments as Viewed by a Survivor of Mengele’s Experiments. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 3–8.
- Pallok, Kristen, De Maio, Fernando, Ansell, David A. (2019). Structural Racism – A 60-Year-Old Black Woman with Breast Cancer, *The New England Journal of Medicine*, 380 (16), April 18, 1489–1493. DOI: 10.1056/NEJMp1811499
- Pozos, Robert S. (1992). Scientific Inquiry and Ethics. The Dachau Data. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 95–108.
- Proctor, Robert N. (1992). Nazi Biomedical Policies. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 23–42.
- Rapa, Mark Josef (2020). The Nazi experiments and data. *The Malta Independent On-Line*, 30 January, available at <https://www.independent.com.mt/articles/2020-01-30/blogs-opinions/The-Nazi-experiments-and-data-6736219060?fbclid=IwAR1KZdBi-DWtCk8U4MQiD-cOJITD7THxK07Qc0jS9BLQZZLzWU8SHCvU278> (accessed 1 February 2020).
- Rattansi, Ali (2007). *Racism: A Very Short Introduction*. Oxford University Press.
- Root, Michael (2017). Race in the Biomedical Sciences. *The Oxford Handbook of Philosophy and Race*. Oxford University Press, 463–473.
- Segal, Nancy L. (1992). Twin Research at Auschwitz-Birkenau: Implications for the Use of Nazi Data Today. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 281–300.
- Seiler Vigorito, Sara (1992). A Profile of Nazi Medicine: The Nazi Doctor-His Methods and Goals. *When Medicine Went Mad: Bioethics and the Holocaust*. Caplan, Arthur L. (Ed.), Humana Press, 9–14.

- Skloot, Rebecca (2010). *The Immortal Life of Henrietta Lacks*. Crown Publishing.
- Skutsch, Carl (2001), Racism. *The Human Rights Encyclopedia*, Volume Three. Carl Skutsch, James Lewis (Eds.). Sharpe Reference, 855–858.
- Teays, Wanda (2019). *Doctors and Torture. Medicine at the Crossroads*. Springer.
- The search for the legacy of the USPHS syphilis study at Tuskegee* (2011). Katz, Ralph V., Warren, Rueben C. (Eds.), Lexington Books.
- Wall, Lewis L. (2006). The medical ethics of Dr J Marion Sims: a fresh look at the historical record, *Journal of Medical Ethics*, 32, 346–350. doi: 10.1136/jme.2005.012559

Medicinski rasizam

SAŽETAK

U radu su analizirani ključni primjeri neetičkog medicinskog eksperimentiranja na ljudima. Prvi dio se bavi rasizmom, njegovom ideologijom i povezanošću s pojmovima medicinskog rasizma. Koncepti rase koji su se prvi put pojavili tijekom kolonijalne ekspanzije definirani su slijedeći njihovo podrijetlo i funkciju, a ne filozofsku misao. Drugi dio govori o autonomiji pacijenata. To uključuje pravo na informirani pristanak, zaštitu privatnosti, pravo na povjerenje i probleme osoba s ograničenom autonomijom, a sve iz povijesne perspektive na medicinski rasizam. U ovom su dijelu odabrani slučajevi medicinskog rasizma pokazali da je razvoj zakonskih propisa i etičkih normi značajno utjecao na medicinsku praksu i zaštitu ispitanika. Povijesni dokazi svjedoče da je, čak i ako je postojala formalna zaštita, bilo odstupanja od nje. Odstupanja su bila usko povezana s društveno-političkom regulacijom i brzim razvojem medicine koji je bio korak ispred etičkih normi. Uz to, ratni zločini protiv čovječnosti bili su povezani s osobnim ideološkim orijentacijama liječnika čija su rasistička, diskriminirajuća uvjerenja bila daleko od medicinske etike i svrhe medicinske prakse. Na kraju se rad bavi pitanjima trebaju li se koristiti rezultati neetičkih i neznanstvenih eksperimenata i kako medicinski rasizam ugrožava ranjive skupine danas.

Ključne riječi: medicinski rasizam, medicinska etika, eksperimentiranje na ljudima, institucijski rasizam, povijest medicine.