

Readings

G.L. Chadwick, "Historical Perspective: Nuremberg, Tuskegee, and the Radiation Experiments," *Journal of the International Association of Physicians in AIDS Care*. Vol 3, No 1 (1997):27-28

Robert Proctor, "Nazi Medicine and the Politics of Knowledge," in *The "Racial" Economy of Science: Toward a Democratic Future*, pp 344-358

James Jones, "The Tuskegee Syphilis Experiment: 'A Moral Astigmatism,'" in *The "Racial" Economy of Science: Toward a Democratic Future*, pp 275-286

World Medical Association Declaration of Helsinki (5 pages)

National Bioethics Advisory Commission, *Ethical and Policy Issues in Research Involving Human Participants*, August 2001, Summary (20 pages):

<http://www.georgetown.edu/research/nrcbl/nbac/pubs.html>

Class Business and Background to New Section

- When unintended consequences lead to racist medical practices that are detrimental to its subjects
- Issues of power—where does power come into play?
- Concepts of racial hygiene from 17th to 19th century—is it feasible to think about how we are going to preserve the most fit from the least fit especially when we look at reproduction technologies
- Foucault and Biopower—how is it that medicine is aligned with the state in promoting public health (pros, cons)?—today with Nazi and Tuskegee—medical research can be used to extent of genocide
- How can science provide authority for those practices?

Blackboard—Racial Hygiene

Carolus Linnaeus (Sweden), 1707-1778

Jean-Baptiste Lamarck, 1744-1829—debate of nature vs nurture, where focused on nurture

Joseph Arthur Comte de Gobineau, 1816-1882, *An Essay on the Inequality of the Races* (1853-1855), wrote about Haitians and considered to be father of racial hygiene who posited that strong hierarchy of races, Aryan nation at top, and those of Nordic background were at the pinnacle (degenerated form were Mediterraneans). Eugenics present in USA, Germany, London, other European nations—and colonies, too, as sites of degeneracy

Discussion of monogenism (common stock) vs polygenism (different races, different stock)—played out in 19th century

20th century—agreed “on monogenism, but there is a hierarchy”

Sir Francis Galton, 1822-1911 >Cousins built on ideas of who should
Charles Darwin, 1809-1882 govern, who should be on top

How policy informs science

Student Presentation:

Articles were more historical than what we’ve been reading

“Historical Perspective: Nuremberg, Tuskegee, and the Radiation Experiments”

Chadwick is professor of medical humanities, human subject research.

- Overview of human subjects experimentation legislation
- Summary: Three causes and effects—something bad, then something ‘good’
 - Nuremberg doctor trials during WWII→Nuremberg Code→Code of Helsinki
 - Tuskegee—institutional review board from Tuskegee; human radiation board
- Will there always be such problems?
 - Yes, research in developing countries for example (Wed)
 - BigPharma documentation—incomplete, slanted—and FDA documentation of experimentation
 - Academic subjects are fairly well protected with red tape with IRBs, hard to work with humans in any capacity to ensure non-harm—but international standards are not the same
- Thalidomide—West Germany drug to reduce morning sickness in pregnant women and led to birth defects
- Willowbrook study in NY (1963-66) had to do with knowingly infecting mentally disabled children with hepatitis into residential facility, questions of consent and assent; injected with various
- Human radiation experiments (1944-74): 4000 experiments by Radiation commission and armed forces with plutonium, radioisotope, nontherapeutic research, on prisoners, nuclear weapons testing, on Marshall Islands and uranium
- 1994 Clinton’s assigned board had difficulties in getting names of patients

“Nazi Medicine and the Politics of Knowledge”

Procter is a historian of science, focuses on history of controversy in science, scientific rhetoric, expert witnessing.

- How Nazis got into power and their persuasive arguments
- Jewish German scientists forced to leave, but Nazi medicine still flourished with select few of the government

- How could this have happened—racial hygiene not just German, but also international phenomenon, but Germans didn't want to be surpassed in racial superiority
- What types of systematic experiments they did from Nuremberg trial:
 - Negative eugenics
 - Forcibly sterilization of mentally inferior people deemed unfit
 - Homosexuals, gypsies, Jews were murdered
 - Medical experiments at Auschwitz, twin studies, and tried to change eye color, surgeries, amputations, nerve regeneration, muscle fiber
 - Dachau, subject to high pressure, high/low temperature, infected prisoners with diphtheria, various contagions to test effectiveness of their treatments
 - Conducted under duress without choice and under racist direction
 - Positive form of eugenics
- Nuremberg Code—the first articulation of informed consent is necessary for any kind of study
- *Biopolitics—that there is attention to a specific population, statistics, etc., in order to promote state security and economics—by promoting a desirable population and stopping another population—what kind of ideal person is being made and where does power claim in here?*
- Heavily segregated—why did this happen in Germany?
 - The idea that we developed the Nuremberg code, but during WWII—what about Japanese doctors? We got results from the Japanese.
 - Japanese internment camps?
 - Overcrowding of doctors
 - To what extent is medical practice transparent to the outside?
 - *Giorgio Agamben—elaborated some of Foucault's ideas, how spaces can develop in a state of exception (times at war, a state where normal civil liberties are brushed aside and where normal moral order is not the same)—and to what extent where everyone's civil liberties always protected? To what extent can a group with power treat a group differently—to what extent are groups who are targets viewed as the equal of other; unequal humanities (blacks, e.g.). What is the status of the group of intervention—class, race?*
- Hereditarian assumption—nature more important than nurture, social problems became biological problems
- The idea that physicians need to protect their physicians—what about checks and balances?
 - Obviously depends on situation
 - Gawande discussed his in M&M conferences—to be a doctor requires confidence; for sake of the field? But need to have checks and balances. Always disequilibrium?

- Should science be allowed to be aligned with politics such that they can target individuals? Should biology be involved in determining policy? Extreme medicalization/biologization
 - Policy that help and hurt some – government has a responsibility to protect all
 - Fixing social ills—sterilizing the newborn addicted to drugs—needs to be social intervention rather than biological/reproductive
 - Where does patient autonomy begin
 - As a conscious choice—trying to harm the baby
 - But controversial because control/choice v gene/biological determined
 - Funding—science must lobby for itself (e.g., stem cells)
 - Economic problems—physicians are not exempt from the times
- Politics and science intertwined—mutually influenced each other; but science claimed depoliticized stance, looking at who was better but never made definitive claims? Freedom of thought—the relationship between politics and science—federal funding (Quote, p 354)
 - Larry Summer’s statements on inherent ability of women, account for differences why women succeed less than men: innate, unwilling to put in effort, social factors; e.g., few white men in the NBA, no Jews in farming, no Catholics in investment banking. Trying to be “provocative”...?
 - Academic freedom by making such comments? Trying to create race or gender—height v intelligence
 - Height is not a power issue; intelligence is
 - Bad use of statistics—The Bell Curve
 - Completely inappropriate statement because of his position and status, representing Harvard; loose causality basis; irresponsible as scientist, highly reputable institution
 - “All-American Dream” for equality—an IDEAL, but reality is a different story
 - Whole branch of medicine dealing with African slaves
- *How do you talk about issues of biological difference that doesn’t strike the ire?*
 - Development of IQ test—made to show that boys could perform better

“The Tuskegee Syphilis Experiment: ‘A Moral Astigmatism’”

- 1932-1972 US Public Health Service conducted study on syphilis on black men with blood tests, autopsies, spinal taps, and non-therapeutic, but presumed therapeutic, vitamins, hot meals, small stipends
- Describes syphilis experiment and if untreated will lead to death
- Patients told they had ‘bad blood’, not syphilis and never told of the current available treatment (which had questionable efficacy)
- Even if totally informed, they were poor, in depression, offered a free meal for testing, burial, and denied treatment elsewhere. Subject compensation puts that ahead of their medical benefits

- Clearly exploiting the patients, their poverty, their need for food—the vulnerability of power; comparable to prostitution—selling your body
- Self-selection of population—certain health profile—not random sample
- Cancer patients now are more willing to participate in new drug trials because that’s all they can afford to get
- *When compensation is a question for survival, e.g. organ selling* (movie: *Dirty Pretty Things*), *questions of power, research subjects*
- Media coverage of these studies—1945, penicillin was widely available and worked, but the study kept going—to observe the onset of the disease, to study untreated syphilis. Why repeat it all?
 - Racial and social issues, compared to Nazi experiments
 - Who kept approving the funding? Why did it keep on going?
 - No formal protocol—kept on going that no one stopped it
 - The organizers really felt that it was a meaningful scientific contribution
 - Who can do science? There is a hierarchy of who can participate—Tuskegee institute—to participate in science
 - Is it ever ethical / legal to observe/study untreated syphilis

World Medical Association Declaration of Helsinki (5 pages)

WMA, international organization represents MDs after WWII, to ensure their independence to work for ethics, care.

- Basic ethical principles: Informed consent; Supervised by clinicians
- Questions—Is the list of principles of WMA—who can enforce or ensure that these are carried out?
- Responsibility to IRB and donors: to what extent does that occur? Is there a policing of studies? Protect confidentiality?
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Wednesday—international trials in developing countries

Ethical and Policy Issues in Research Involving Human Participants