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The Tuskegee Syphilis Experiment
The Implications of its Legacy

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October 1, 2020
OBJECTIVES

- Discuss details of the Tuskegee Study
- Summarize ethical issues
- Explore the legacy of Tuskegee
  - Distrust of the Medical Establishment
The Tuskegee Syphilis Experiment

Present-day significance:

- For many African-Americans, the Study has become a symbol of their mistreatment by the medical establishment
- Vulnerable populations: Symbolizes the potential for exploitation
- A metaphor for deceit, conspiracy, malpractice and neglect, systemic/structural racism, if not outright racial genocide
BAD BLOOD


James Jones

- Professor of history at the University of Houston
- Kennedy Fellowship in Bioethics at Harvard University
The Tuskegee Syphilis Experiment

Most basic definition:

- A study of the effects of “untreated” syphilis in African-American males

Reality:

- A non-therapeutic experiment to compile data on the effects of “undertreated” syphilis in African-American males
- Nothing to do with treatment
- No new drugs tested
- No effort to study efficacy of old treatments
The Tuskegee Syphilis Experiment

- 1932-1972 (over 40 years!)
- 400 African-American men
  - Never informed that they had syphilis
  - Unknowingly infected their wives and partners
  - Unknowingly passed it congenitally to their offspring
Factors leading to the Tuskegee Study

INITIAL GOOD INTENTIONS:

- 1929 - United States Public Health Service (USPHS)
  - Provide improved medical services to prevent syphilis and promote cure
  - A project to control venereal disease
  - First-line treatment
    - Arsenic compounds and mercury salts
      - Recommended over the alternative choice of NO treatment
  - Ultimate goal: Render people non-infectious, cured
Factors leading to the Tuskegee Study II
SITE SELECTION:

- Macon County, Alabama
  - Selected as test center for pioneering community-wide syphilis control program
  - High prevalence of syphilis in the area
    - 35-40% of all age groups tested positive for syphilis
  - Rosenwald Fund
    - Charitable organization committed to improving health and living conditions of African-Americans
Macon County, Alabama

Macon County in 1929:

- African-American sharecroppers and day laborers
- Poor and illiterate
- Initial recruitment of participants:
  
  “Government doctors are coming to test for BAD BLOOD”
BAD BLOOD

- Common generic phrase understood by the community
  - Rheumatoid arthritis
  - Headaches
  - Peptic ulcer disease

- Catchall Phrase, not limited to the symptoms of syphilis

- USPHS withheld specific ailment and treatment program
  - Counterintuitive for a program aimed to control the spread of syphilis
Factors leading to the Tuskegee Study III
TWO YEARS OF TREATMENT:

- **1929-1931**
  - Community-wide treatment program, arsenic and mercury, aimed at controlling syphilis

- **1932**
  - Great Depression: Rosenwald Fund discontinues funding
1932:
Birth of the Tuskegee Study

“Salvage a Scientific Experiment”
USPHS seeks to “salvage something from the data”
- “Unparalleled opportunity for the study of untreated syphilis”

1932:
- Science had proven no racial differences in etiology (spirochete) or treatment of syphilis
- Leading authorities believed clinical manifestations of syphilis different in African-Americans and Caucasians
  - Retrospective study 1891-1929 in Oslo, Sweden
Devising the Salvage Experiment I: Methodology

- 400 African-American males with syphilis selected from original study (vs. 201 controls)
- Study would last for 6-12 months
- Permission needed from local medical societies
  - USPHS promised to provide ALL men with some form of treatment
    - ALL men in this “untreated” study received TREATMENT
Devising the Salvage Experiment II: Retaining the Subjects

- Incentives for participation
  - Free physical exams
  - Free hot meals and transportation
  - Free treatment of minor ailments
  - Guarantee of burial stipends paid to survivors
    - $50 in 1932 dollars - the only form of burial insurance any of the participants had
DATA COLLECTION:
Documenting Asymptomatic Neurosyphilis

- Physical exam not definitive / objective
- Tap all participants
- 1932 Spinal taps
  - not as developed as today, many side effects
  - USPHS decides to conduct mass spinal taps to avoid participants telling each other about harsh side effects
“Dear Sir,

Some time ago you were given a thorough examination and since that time we hope you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special *treatment* (emphasis is mine) if it is believed you are in a condition to stand it.

Remember this is your last chance for a special free treatment. Be sure to meet the Nurse!

Signed, Macon County Health Department
Spinal Taps

- Concealed fact that procedure was **diagnostic** rather than **therapeutic**
- Men had received injections with neoarsphenamine in past; assumed shots associated with therapy
- >20% complained of side effects for years after the taps
- Residue of fear and mistrust created
An “Open-ended” Study

1933: USPHS reconvened to discuss study:

- Continue observation of infected African-American males
- Eventually bring men to autopsy
- Continue periodic physical exams
- Since small amounts of treatment ran out, give placebos to men who ask for treatment
Withholding Penicillin

- **1943**: Penicillin proven effective
  - Local treatment clinics sent letter by USPHS with list of men to exclude from treatment
  - Patients told burial stipend forfeited if men accepted Penicillin treatment

- **1953**: Penicillin **Standard of Care**
  - USPHS insisted study must continue: “It makes the experiment a never-again-to-be-repeated opportunity”
The Tuskegee Experiment: SCIENTIFIC ANALYSIS

- All men at least minimally treated
  - Unknown what small amount of treatment had on evolution of disease
  - USPHS blind to the fact that “untreated” study contaminated by “treatment”
  - NO value when discussing untreated syphilis; at most undertreated syphilis
The Tuskegee Experiment: ETHICAL ANALYSIS

Ethics in Historic Context:

Are we trying to apply present-day standards to actions of 1932?

*Nuremberg Code (late 1940’s)*
Basic principles of the Nuremberg Code

- **Article I:** The *voluntary consent* of the human subject is absolutely essential...[he] should have *sufficient knowledge and comprehension*...should be made known to him the *nature, duration and purpose* of the experiment

- **Article VI:** The *degree of risk* to be taken *should never exceed* that determined by the *humanitarian importance of the problem* to be solved by the experiment
Basic principles of the Nuremberg Code

- Article IX: During the course of the experiment, the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.
The Tuskegee Experiment: ETHICAL ANALYSIS I

Denial of proven Standard of Care treatment

- **1932**: Mercury, Arsenic standard of care
- **1940’s**: Penicillin introduced, denied
- **1953**: Penicillin standard of care; subjects threatened
The Tuskegee Experiment: ETHICAL ANALYSIS II

Lack of informed consent, overt lying

- **Never Told:**
  - Study of syphilis, just “Bad Blood”
  - Treatment withheld

- **Told:**
  - Treatment for ailments “rheumatism, bad stomachs”
  - Diagnostic taps were a form of treatment
  - Dropped from study, forfeit burial stipend, if attempt to receive treatment elsewhere
Ultimate reason study continued for over 40 years

- “A minimal sense of personal responsibility and ethical concern among the small group of men within the USPHS who controlled the study”
- Physician Complacency?
- Systemic Racism
Ending the Study

- **1965**: Peter Buxton, hired by USPHS - venereal disease interviewer
- **1966**: P.B. learned of study, sent letter, no reply
- **1967**: P.B. resigned voluntarily from USPHS without any response
- **1968**: P.B. sent second letter

- **1969**: Blue Ribbon Panel
  - All MD’s, no African-Americans, no persons trained in medical ethics
  - “You will never have another study like this -- take advantage of it”

- **1972**: Buxton tells Edith Lederer (AP reported, SF), tells Jean Heller (AP, Washington), breaks story on 7/25/72 - Washington Star
‘NOW can we give him penicillin?’

Editorial cartoon by Tony Auth, Philadelphia Inquirer, July 1972. (Courtesy Tony Auth)
Editorial cartoon by Lou Erikson, Atlanta Constitution, July 1972. (Courtesy Lou Erikson)

SECRET
TUSKEGEE
STUDY
free autopsy
free burial
plus $100 BONUS!
Aftermath

- **1972-73**: Senator Edward Kennedy Hearings
- **1973**: 1.8 billion class-action lawsuit on behalf of men in study
- **1974**: US Gov’t pays 10 million in out-of-court settlement
  - $37,500 to “living” syphilitics
  - $15,000 to heirs of “deceased” syphilitics
- No apology from USPHS
- No admission of personal wrongdoing
- No apology from US Government until 1997 - Clinton apologizes:
  “The legacy of the study at Tuskegee has reached far and deep, in ways that hurt our progress and divide our nation. We cannot be one America when a whole segment of our nation has no trust in America”
Current Medical Implications of The Tuskegee Syphilis Study
TUSKEGEE LEGACY: 
Formation of Strict Guidelines 
Regarding Human Experimentation

- Revamping of HEW regulations on protection of human subjects in experimentation
- Belmont Report
  - Respect for persons, voluntary consent
  - Beneficence, Nonmaleficence
  - Justice
- Institutional Review Boards (IRBs) 1985
  - Committees organized to review any research project involving human subjects
Understanding the Legacy of Tuskegee:
One abuse of many / Not an isolated event

Historically-constructed attitude:

- Slavery (medical experimentation - Dr. Sims, father of modern gynecology)
- Sharecropping
- Lynchings (dehumanization of African-American bodies)
- Jim Crow laws (separate and “unequal”)
- Disenfranchisement
- Residential segregation
- Barred from hospitals
- Job discrimination
Legacy of Tuskegee: Distrust of the Medical Establishment

Distrust has lead to:

- Low participation in organ donation
- Low immunization rates
- Reluctance to seek routine preventive care
- Low participation in clinical trials
- Conspiracy theories
  - AIDS as a form of “genocide”
Distrust Documented: Low Participation in Clinical Trials

National telephone survey on participation in clinical research:
527 African-American respondents/382 white respondents
Outcome measure: 7-item index of distrust

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<tr>
<th></th>
<th>African-American</th>
<th>White</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not trust that physician would fully explain research participation</td>
<td>42%</td>
<td>23%</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Research participant used as a ‘guinea pig’ without consent</td>
<td>79%</td>
<td>52%</td>
<td>&lt;.01</td>
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<tr>
<td>Physicians often prescribed medication as a way of experimenting on people without consent</td>
<td>63%</td>
<td>38%</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Physicians give treatments as part of an experiment without permission</td>
<td>25%</td>
<td>8%</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

Archives of Int. Medicine
November 25, 2002
Archives of Internal Medicine, 11/02 Results:

- African-American respondents had significantly higher mean distrust score (3.1 v 1.8, P<.01)
- After controlling for sociodemographic variables (sex, lower educational attainment, unemployment, geographic region), race remained strongly associated with a higher distrust score
Legacy of Tuskegee:
Distrust leads to Conspiracy Theories

The memories of Tuskegee have led many to think:

- “The Government and medical community are out to harm African-Americans like they did in the Tuskegee Study”
- “If they did it THEN, they could do it NOW”

Dr. Donald Printz, an official at the Venereal Disease Branch of the CDC (1972) reported the following about the Tuskegee Study:

“…Like a genocide…a literal death sentence was passed on those people”
Distrust:
Conspiracy Theories about Whites (The Gov’t) against African-Americans

- The men of the Tuskegee Study were injected with syphilis
- Government promotes drug abuse in African-American communities
- HIV is a man-made weapon of racial warfare
- AIDS is a form of genocide
  - The Nation of Islam
  - The Los Angeles Sentinel (1989)
  - *Essence* magazine (1990)
“Efforts to develop needle distribution programs have been stymied by…claims that such programs have a genocidal impact on African-American communities.

In many communities where drug abuse is epidemic, needle distribution programs are perceived as contributing to the drug problem, particularly when such programs [occur] in the absence of access to adequate drug treatment services.

The image of African-American drug users reaching out for treatment, only to receive clean needles from public health authorities, provides fuel for the genocidal theory.”

1990: SCLC, with CDC funding

- National HIV Education Program
- RACE: Reducing AIDS through Community Education
- Survey of 1056 African-American churches in 5 cities:
  - Atlanta, GA
  - Charlotte, NC
  - Detroit, MI
  - Kansas City, MO
  - Tuscaloosa, AL
SCLC HIV Educational Survey: Results

- 35% believed AIDS as a form of genocide, 30% unsure (65%)
- 44% believed the Gov’t is not telling the truth about AIDS, 35% unsure (79%)
- 34% believed HIV is a man-made virus, 44% unsure (78%)
Covid-19

- Disproportionate impact on African-American (as well as Latinx) populations
- Vaccine trials need heterogeneous patients to ensure effectiveness
- Distrust caused by Tuskegee and history of structural racism make it very difficult to recruit participants
Mainstream Responses to Conspiracy Theories

  - “Bizarre”
  - “Astonishing”
  - “Paranoid”
Despite the prevailing distrust, is there evidence to suggest that today’s minority populations are receiving substandard care?
Institute of Medicine (IOM) report:

- Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare (March 2002)
  - Committee reviewed > 100 studies that assessed the quality of healthcare for various racial and ethnic minorities
  - Confounding variables controlled:
    - Insurance status
    - Patient Income
    - Access-related factors
    - Age, gender
    - Where care is received (public v. private)
    - Co-morbid illnesses
IOM report: Unequal Treatment II

Results:

- Minorities less likely than whites to receive needed services, including clinically necessary procedures
- Disparities exist in several disease areas:
  - Cancer
  - Cardiovascular disease
  - HIV/AIDS
  - Diabetes
  - Mental illness
  - A range of procedures
Factors that may contribute to disparities in healthcare:

I. Factors related to operation of healthcare systems
   • Cultural/linguistic barriers (lack of interpretation services for those with limited English proficiency)
   • Fragmented healthcare systems (lower-cost health plan placing greater per-patient limits on healthcare expenditures and available services)
   • Incentives to control costs (incentive for physician to limit services)

II. Factors related to the clinical encounter
   • Provider’s side of exchange:
     ✓ Bias (or prejudice) against minorities
     ✓ Greater clinical uncertainty when interacting with minority patients
     ✓ Beliefs (stereotypes) held by provider about the behavior or health of minorities
   • Patient’s side of exchange:
     ✓ Reaction to provider’s behavior associated with above practices (Distrust)
Suggestions to eliminate disparities in care:

- Education / Understanding that disparities DO exist, despite providers’ best intentions
- Cross-cultural education: awareness of how cultural and social factors influence healthcare
- Policy and regulatory strategies that address fragmentation of health plans along socioeconomic lines
Overcoming Barriers I

- **Participation in Clinical Trials**
  - Simple compliance with protection of human subjects procedures may not be enough
  - Must be fully informed about research procedures, costs, benefits
    - Doctor-patient relationship has the potential to raise trust
    - Established clinical relationship (and open communication that it fosters) may be necessary before a discussion of risks and benefits takes place
  - Minority representation on research advisory committees
Overcoming Barriers II

- **Discuss fear of genocide evoked by history of racism within Medicine**
  - Importance of having an appreciation of the significance of Tuskegee
  - Ignoring may lead to loss of believability and further alienation
  - Discussing may help regain credibility and public trust

- **Culturally-sensitive community-based education programs**
  - Involvement of community members in program planning and evaluation efforts
    - COPC (community-oriented primary care) as a model for community involvement
  - Program staff that are indigenous to community
Lessons from Tuskegee

- Distrust is not unwarranted, bizarre, or paranoid.
- Understanding the source of distrust can bridge gaps.
- The importance of questioning and challenging unethical behavior.
- The Tuskegee study "revealed more about the pathology of racism than it did about the pathology of syphilis."
Suggestions for further reading


Corbie-Smith G. Distrust, Race, and Research. Arch Intern Med 2002;162:2458-2463


