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## The Tuskegee Syphilis Experiment: The Implications of its Legacy

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# **The Tuskegee Syphilis Experiment**

## **The Implications of its Legacy**

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October 1, 2020

# OBJECTIVES

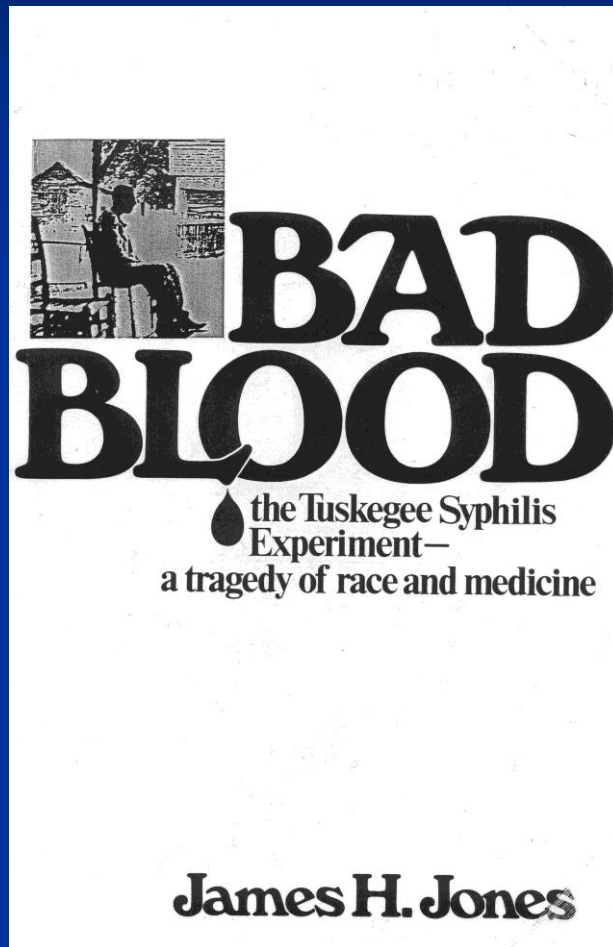
- Discuss details of the Tuskegee Study
- Summarize ethical issues
- Explore the legacy of Tuskegee
  - Distrust of the Medical Establishment

# 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

- *New York Times* Best Books of 1981

## James Jones

- Professor of history at the University of Houston
- Kennedy Fellowship in Bioethics at Harvard University

# The Tuskegee Syphilis Experiment

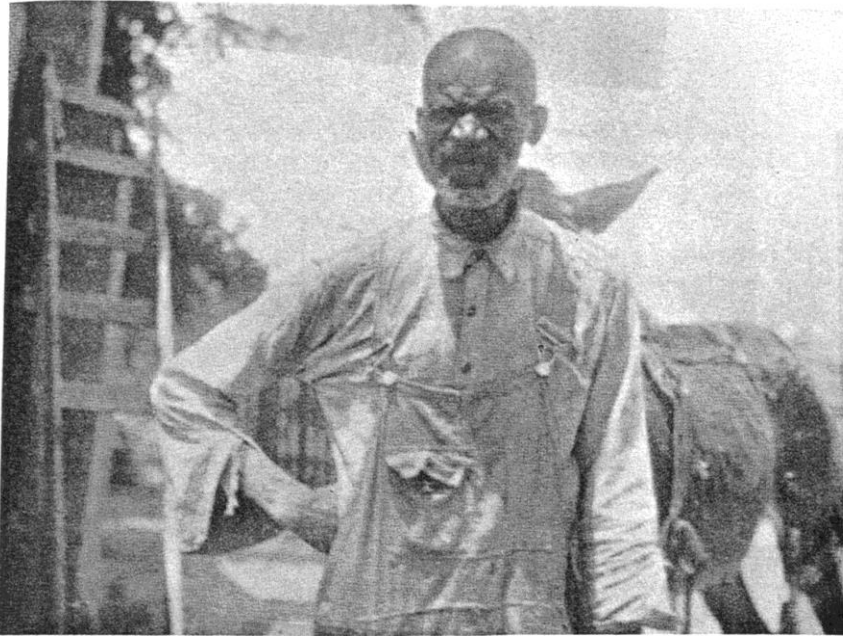
Most basic definition:

- 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



"Dis ole mule lak' me—he ain't much good no more." (*Johnson, Shadow of the Plantation*)

- 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

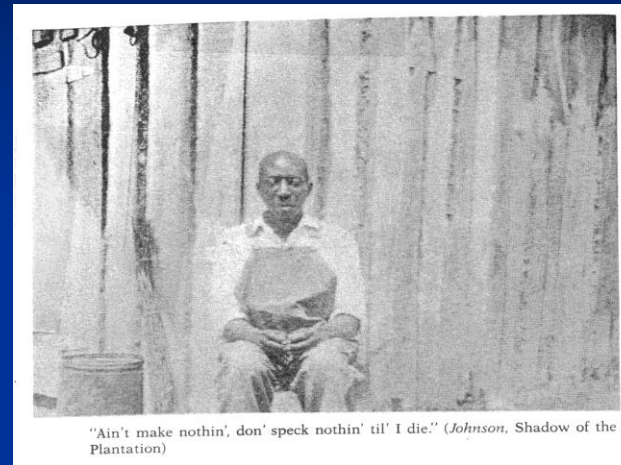
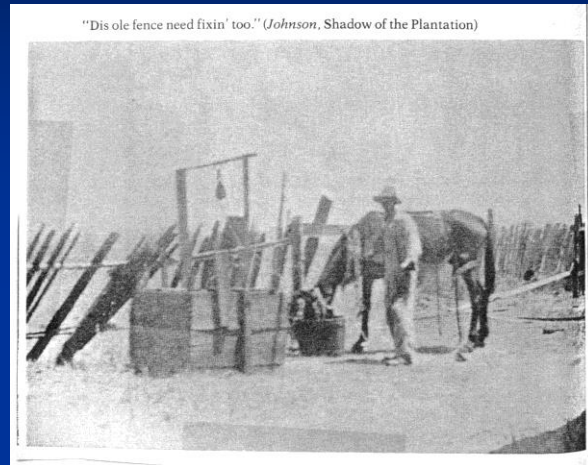
## SITE SELECTION:



- 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”**

# Birth of Tuskegee: Salvaging the Data

- 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,

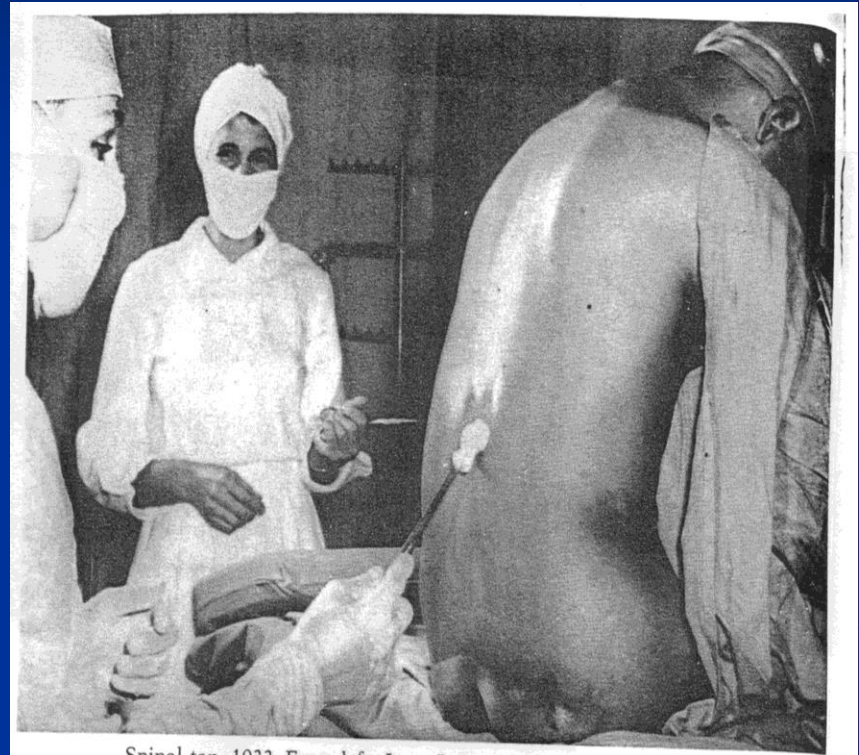
Some time ago you were given a thorough examination and since that time we hope you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special treatment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



Spinal tap, 1933. From left: Jesse J. Peters, Nurse Rivers, and unidentified subject. (Center for Disease Control, Atlanta, Ga.)



# 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

Below left: Case of ulcerated cutaneous syphilis on left leg, photographed from rear. (Center for Disease Control, Atlanta, Ga.) Below right: Case of ulcerated cutaneous syphilis on right arm (Center for Disease Control, Atlanta, Ga.)



# 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

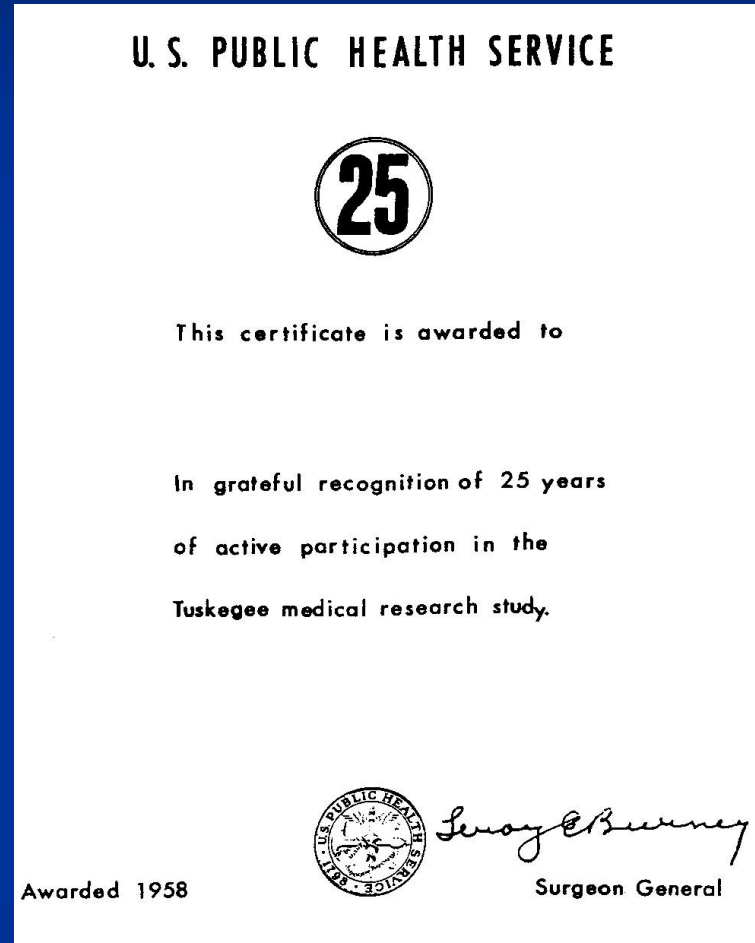
## Lack of informed consent, overt lying

- *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





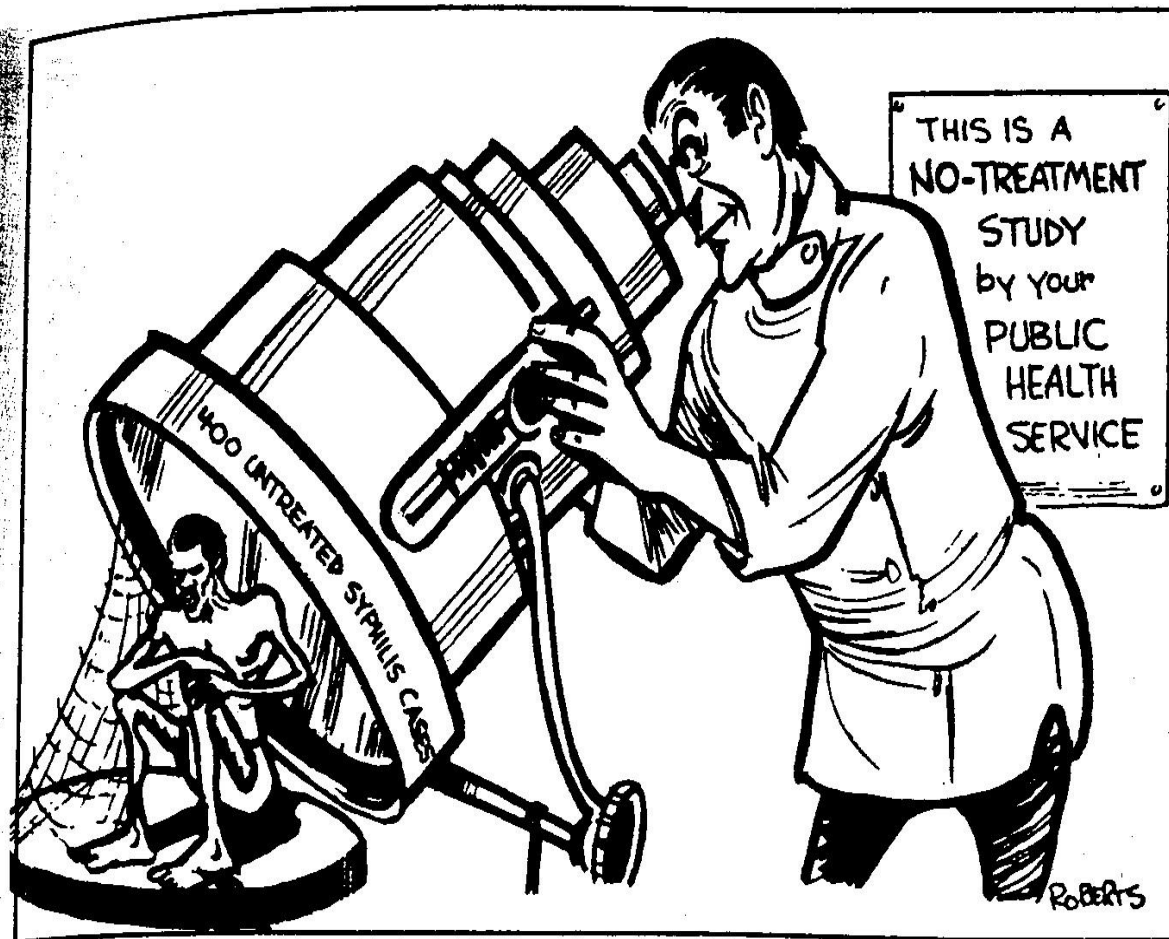
# Ending the Study

- 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?'**

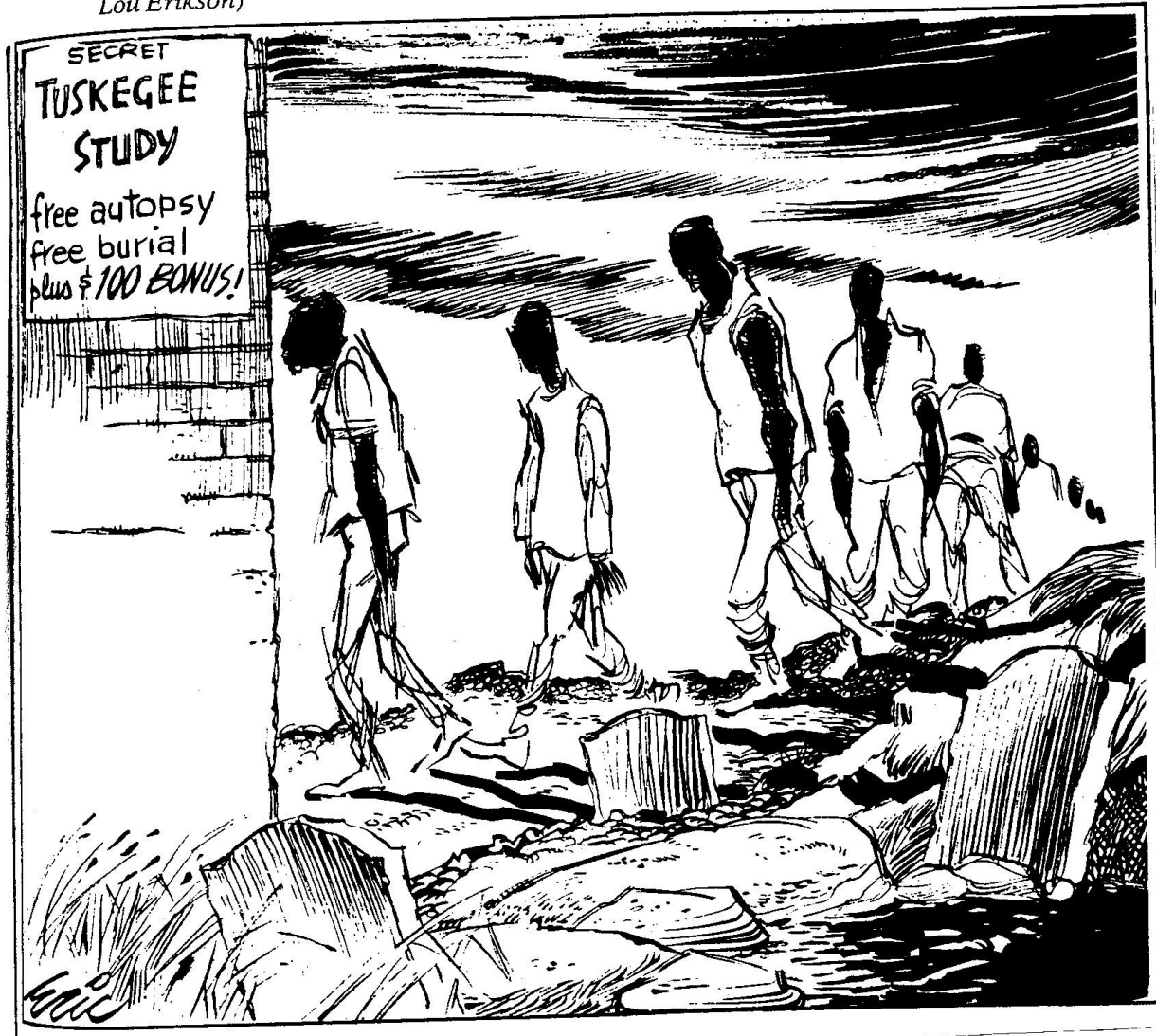
Editorial cartoon by Tony Auth, *Philadelphia Inquirer*, July 1972. (Courtesy Tony Auth)



Editorial cartoon by "Roberts," *Rocky Mountain News*, Denver, Colorado, July 1972. (Library of Congress)



Editorial cartoon by Lou Erikson, *Atlanta Constitution*, July 1972. (Courtesy Lou Erikson)



# 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

	African-American	White	P-value
Do not trust that physician would fully explain research participation	42%	23%	<.01
Research participant used as a 'guinea pig' without consent	79%	52%	<.01
Physicians often prescribed medication as a way of experimenting on people without consent	63%	38%	<.01
Physicians give treatments as part of an experiment without permission	25%	8%	<.01

Archives of Int. Medicine  
November 25, 2002

# Distrust, Race, and Research

## *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)

# **Tuskegee Legacy: Conspiracy theories stymie HIV prevention efforts**

“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.”

American Journal of Public Health (1991)

# Tuskegee Legacy: Conspiracy theories documented during HIV educational efforts

- 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

- New York Times Editorial (1992)
  - “Bizarre”
  - “Astonishing”
  - “Paranoid”

**Despite the prevailing  
distrust,  
Is there evidence to suggest  
that today's minority  
populations are receiving  
substandard care?**

# Institute of Medicine report: UNEQUAL TREATMENT

- 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

# IOM report: *Unequal Treatment III*

## 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)



# IOM report: *Unequal Treatment IV*

## 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 source of distrust can bridge gaps
- 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

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