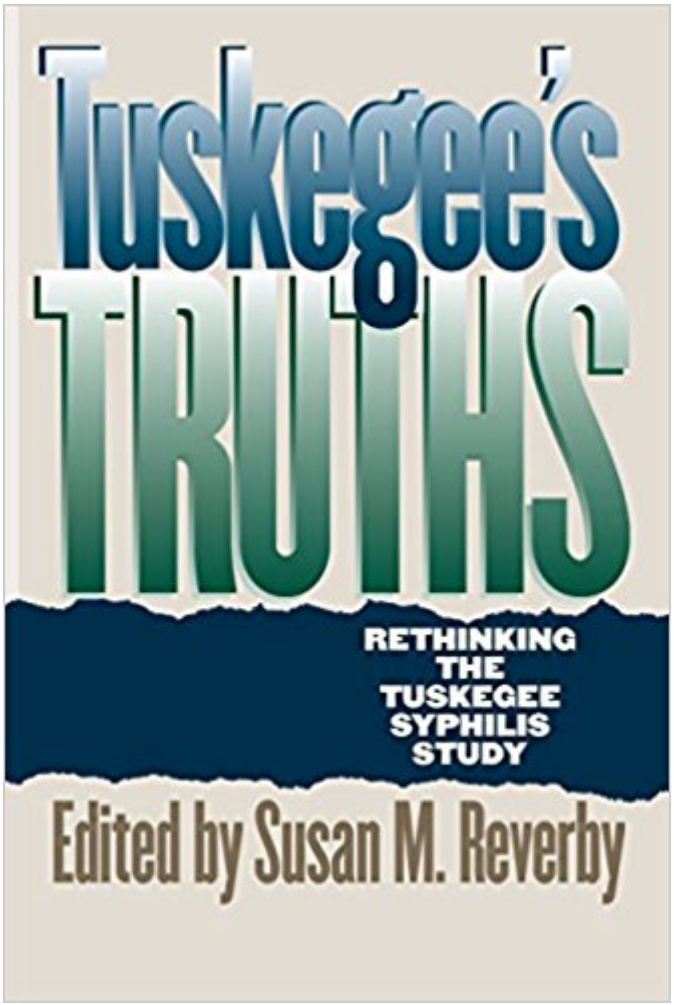
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Tuskegee's Truths: Rethinking The Tuskegee Syphilis Study (Studies In Social Medicine)



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Synopsis

Between 1932 and 1972, approximately six hundred African American men in Alabama served as unwitting guinea pigs in what is now considered one of the worst examples of arrogance, racism, and duplicity in American medical research--the Tuskegee syphilis study. Told they were being treated for "bad blood," the nearly four hundred men with late-stage syphilis and two hundred disease-free men who served as controls were kept away from appropriate treatment and plied instead with placebos, nursing visits, and the promise of decent burials. Despite the publication of more than a dozen reports in respected medical and public health journals, the study continued for forty years, until extensive media coverage finally brought the experiment to wider public knowledge and forced its end.This edited volume gathers articles, contemporary newspaper accounts, selections from reports and letters, reconsiderations of the study by many of its principal actors, and works of fiction, drama, and poetry to tell the Tuskegee story as never before. Together, these pieces illuminate the ethical issues at play from a remarkable breadth of perspectives and offer an unparalleled look at how the study has been understood over time.

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Customer Reviews

Tuskegee’s Truths: Rethinking the Tuskegee Syphilis Study revisits the infamous Tuskegee Study and explores its contemporary meanings and relevance for American society. The Tuskegee Study

was an experiment conducted by the U.S. Public Health Service from 1932 to 1972. Researchers observed the effects of advanced syphilis on 399 poor black sharecroppers from Macon County, Alabama, who were followed clinically but not treated, even after the introduction of penicillin therapy in 1943. The book's editor, a professor of women's studies at Wellesley College, argues that the Tuskegee Study stands out amid a shameful history of unethical medical research. Like many other examples of unethical research, the study reveals how government officials deceive, how methods to protect human subjects fail, how research exploits human beings, how economically and socially disadvantaged groups are taken advantage of, and how human rights are violated and the violations sustained. The Tuskegee Study shares these common failings and also carries distinct lessons of its own. These lessons emerge as "truths" when we look at this research as a powerful metaphor for racism in American society. "Tuskegee's truths," as the book's title suggests, remain true today because victimization by racist means endures. The racist climate of American society during the days of the Tuskegee Study did not end abruptly with the 1972 press release that led to the termination of the study. Instead, the truths of Tuskegee are troubling precisely because we cannot write them off as merely historical. As President Clinton reflected in his 1996 public apology to the survivors of the study and their families, we must work continually to involve minority communities in research and health care, educate medical researchers in bioethics, involve minority groups in bioethics programs, and earn and keep the trust of research subjects who are members of disadvantaged and minority groups. While retaining this central focus, the book investigates the problem of racism in medical research at multiple levels. With articles and documents spanning more than 600 pages, the book brings together an impressive array of physicians, historians of medicine and science, sociologists, government officials, attorneys, bioethicists, poets, and others. Scholarly essays explore class, sex, and sexuality. Historical records document interviews, correspondence, and testimony by researchers, subjects, and government officials. Ethical debates reveal contrasting positions about the role of race in contemporary medical-research controversies. Also included are excerpts from a controversial play and Emmy Award-winning movie, excerpts from the 1973 U.S. Senate hearings on human experimentation, a discussion of the 1973 lawsuit filed by survivors and their heirs by the noted civil-rights attorney for the plaintiffs, and President Clinton's 1996 public apology. Particularly noteworthy contributions include King's essay on the "dilemma of difference." As King explains, researchers in the 1930s believed that the natural course of untreated syphilis in blacks and whites was not the same and that racial differences extended to psychological and social responses to the disease. This created an ethical dilemma about how to respond to perceived differences. On the one hand, if medicine

ignores differences and treats all groups similarly, unintended harms may occur as a result of the failure to recognize differences. On the other hand, if medicine pays attention to differences by studying and responding to them, the effort may reinforce negative stereotypes or lead society to overlook the economic or social factors contributing to differences among groups. A vivid example of this dilemma is discussed by Angell, who notes that one justification for the Tuskegee Study was the fact that the impoverished black men involved in the study would in all likelihood not have received treatment for their syphilis anyway, so the investigators were merely observing what would have happened if there had been no study. Rather than seeking to correct or condemn this injustice, the Tuskegee Study accepted it, even arguing that results of the experiment would benefit poor, rural blacks because of their high rate of untreated syphilis. The dilemma about difference is evident today in debates about the disproportionately low participation of black Americans in clinical AIDS trials in comparison with the number of blacks who have been infected with the human immunodeficiency virus (HIV). The dilemma is also apparent in recent discussions of the ethics of withholding treatment from pregnant women participating in research studies in Third World countries on the use of zidovudine to prevent maternal-fetal transmission of HIV. The book's contributors explore these contemporary examples and offer differing viewpoints. Other questions addressed in this book include the following. Should physicians use the Tuskegee Study findings? What other historical examples contribute to distrust of the medical profession among black Americans? Are past decisions and actions morally relative to the standards and social circumstances of the times in which they occurred? How do published scientific writings obscure ethical issues? Why is the plight of women and children who were infected with syphilis from untreated men in the Tuskegee Study largely ignored? How should we understand the role of black professionals who did not protest the Tuskegee Study? How does one's race, sex, sexuality, class, and professional status encourage deference or speaking out about moral error? How well does the book achieve its goal of teaching "Tuskegee's truths" and revealing their relevance today? The truths are presented all the more forcefully because they emerge from distinct perspectives: history, medicine, bioethics, law, and literature. The retelling of the Tuskegee story gains credibility because the book incorporates so much firsthand testimony. The editor wisely invites the reader to struggle with and discover the lessons of the Tuskegee Study. The book succeeds admirably. Its comprehensive scope makes it an invaluable reference tool. Its sharp focus on race will attract the attention of scholars of race as well as historians and ethicists concerned with racism in medicine and medical research. Nancy Jecker, Ph.D. Copyright Ã Â© 2000 Massachusetts Medical Society. All rights reserved. The New England Journal of Medicine is a registered trademark of the MMS.

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Definitive. Comprehensive. Painful. A well-selected set of primary materials, analytical articles, etc. If you want to know about the Tuskegee Syphilis Experiment, this is your bible.

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