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Medical Apartheid

*The Dark History of Medical Experimentation
on Black Americans from Colonial
Times to the Present/ 1*

Harriet A. Washington



MEDICAL

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**The Dark History of Medical
Experimentation on Black Americans
from Colonial Times to the Present**

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*For Ron DeBose, my husband,
with undying love and gratitude*

When I began working at the institute, I recalled my adolescent dream of becoming a medical research worker. Daily I saw young...[white] boys and girls receiving instruction in chemistry and medicine that the average black boy or girl could never receive. When I was alone, I wandered and poked my fingers into strange chemicals, watched intricate machines trace red and black lines upon ruled paper. At times I paused and stared at the walls of the rooms, at the floors, at the wide desks at which the white doctors sat; and I realized—with a feeling that I could never quite get used to—that I was looking at the world of another race.

—RICHARD WRIGHT, 1944

The wrongs which we seek to condemn and punish have been so calculated, so malignant and so devastating that civilization cannot tolerate their being ignored because it cannot survive their being repeated.

—CHIEF U.S. PROSECUTOR ROBERT JACKSON, OPENING STATEMENT, NUREMBERG DOCTORS' TRIAL, DECEMBER 9, 1946

INTRODUCTION

The American Janus of Medicine and Race

Science without conscience is the soul's perdition.

—FRANÇOIS RABELAIS, PANTAGRUEL

On a sylvan stretch of New York's patrician upper Fifth Avenue, just across from the New York Academy of Medicine, a colossus in marble, august inscriptions, and a bas-relief caduceus grace a memorial bordering Central Park. These laurels venerate the surgeon James Marion Sims, M.D., as a selfless benefactor of women. Nor is this the only statuary erected in honor of Dr. Sims. Marble monuments to his skill, benevolence, and humanity guard his native South Carolina's statehouse, its medical school, the Alabama capitol grounds, and a French hospital. In the mid-nineteenth century, Dr. Sims dedicated his career to the care and cure of women's disorders and opened the nation's first hospital for women in New York City. He attended French royalty, his Grecian visage inspired oil portraits, and in 1875, he was elected president of the American Medical Association. Hospitals still bear his name, including a West African hospital that utilizes the eponymous gynecological instruments that he first invented for surgeries upon black female slaves in the 1840s.

But this benevolent image vies with the detached Marion Sims portrayed in Robert Thom's *J. Marion Sims: Gynecologic Surgeon*, an oil representation of an experimental surgery upon his powerless slave Betsey. Sims stands aloof, arms folded, one hand holding a metroscope (the forerunner of the speculum) as he regards the kneeling woman in a coolly evaluative medical gaze. His tie and morning coat contrast with her simple servants' dress, head rag, and bare feet.

The painting, commissioned and distributed by the Parke-Davis pharmaceutical house more than a century after the surgeries as one of its

A History of Medicine in Pictures series, takes telling liberties with the historical facts. Thom portrays Betsey as a fully clothed, calm slave woman who kneels complacently on a small table, hand modestly raised to her breast, before a trio of white male physicians. Two other slave women peer around a sheet, apparently hung for modesty's sake, in a childlike display of curiosity. This innocuous tableau could hardly differ more from the gruesome reality in which each surgical scene was a violent struggle between the slaves and physicians and each woman's body was a bloodied battleground. Each naked, unanesthetized slave woman had to be forcibly restrained by the other physicians through her shrieks of agony as Sims determinedly sliced, then sutured her genitalia. The other doctors, who could, fled when they could bear the horrific scenes no longer. It then fell to the women to restrain one another.

I wanted to reproduce Thom's painting on the cover of this book, or at least in the text, but when I asked permission of its copyright holder, Pfizer Inc., the company insisted on reviewing the entire manuscript of this book before making a decision. As an independent scholar I could not acquiesce to this, and I used another cover image. When I renewed my request to use the image within the text, Pfizer agreed to base its decision upon reading this chapter and an outline of the book.

The Pfizer executives apparently were uncomfortable with what they read, because they refused to grant permission to reproduce this telling image or even respond to my query after I supplied the requested chapter and outline. This act of censorship exemplifies the barriers some choose to erect in order to veil the history of unconscionable medical research with blacks.

Betsey's voice has been silenced by history, but as one reads Sims's biographers and his own memoirs, a haughty, self-absorbed researcher emerges, a man who bought black women slaves and addicted them to morphine in order to perform dozens of exquisitely painful, distressingly intimate vaginal surgeries. Not until he had experimented with his surgeries on Betsey and her fellow slaves for years did Sims essay to cure white women.

Was Sims a savior or a sadist? It depends, I suppose, on the color of the women you ask. Marion Sims epitomizes the two faces—one benign, one

malevolent—of American medical research.

“Of all the forms of inequality, injustice in health is the most shocking and the most inhumane.” In 1965, Martin Luther King, Jr., spoke these words in Montgomery, Alabama, at the end of the Selma to Montgomery march that had been attended by the black and white physicians of the Medical Committee for Human Rights. King had invited the doctors not only to give medical succor to injured marchers but also to witness the abuse suffered at the hands of segregationists. With these almost unnoticed words, King ushered in a new era in civil rights, because as Delegate to Congress Donna Christian-Christensen, M.D., chair of the Congressional Black Caucus Health Braintrust, has declared, “Health disparities are the civil rights issue of the 21st century.” Thus Dr. King’s alarm over racial health injustice was prescient, and were he alive today, his concern would be redoubled. Mounting evidence of the racial health divide confronts us everywhere we look, from doubled black infant death rates to African American life expectancies that fall years behind whites’. Infant mortality of African Americans is twice that of whites, and black babies born in more racially segregated cities have higher rates of mortality. The life expectancy of African Americans is as much as six years less than that of whites.

Old measures of health not only have failed to improve significantly but have stayed the same: some have even worsened. Mainstream newspapers and magazines often report disease in an ethnocentric manner that shrouds its true cost among African Americans. For example, despite the heavy emphasis on genetic ailments among blacks, fewer than 0.5 percent of black deaths—that’s less than one death in two hundred—can be attributed to hereditary disorders such as sickle-cell anemia. A closer look at the troubling numbers reveals that blacks are dying not of exotic, incurable, poorly understood illnesses nor of genetic diseases that target only them, but rather from common ailments that are more often prevented and treated among whites than among blacks.

Three times as many African Americans were diagnosed with diabetes in 1993 as in 1963. This rate is nearly twice that of white Americans and is sorely underestimated: The real black diabetes rate is probably double that of whites. As with most chronic diseases, African Americans suffer more complications, including limb loss, blindness, kidney disease, and terminal

heart disease. Cancer, the nation's second greatest killer, is diagnosed later in blacks and carries off proportionately more African Americans than whites. African Americans suffer the nation's highest rate of cancer and cancer deaths.

The distortion of African American death rates is illustrated by the common dismissal of black women's breast-cancer risks as "lower than white women's." This characterization implies that black women are at low risk from breast cancer, but their risk is only *slightly* lower, because the estimated lifetime risk of developing breast cancer is ten per one hundred for white women born in 1980, and seven per one hundred for black women born that year. Moreover, this lower risk of developing breast cancer is overshadowed by blacks' much higher risk of dying from it: Eighty-six percent of white women with breast cancer are alive five years later; only 71 percent of black women survive that long. A black woman is 2.2 times as likely as a white woman to die of breast cancer. Black women have been undergoing mammograms at the same rate as white women but are more likely to receive poorer-quality screening, which may not detect a cancer in time for a cure. A black woman is also more likely to develop her cancer before age forty, too early for recommended mammograms to catch it, and black women are diagnosed at a more advanced stage than either Hispanic or white breast-cancer patients. Black breast-cancer patients have a worse overall prognosis, and a worse prognosis at each stage. Black men have the nation's highest rates of developing and of dying from prostate and lung cancers.

Despite its image as a disease that affects middle-aged white men, heart disease claims 50 percent more African Americans than whites and African Americans die from heart attacks at a higher rate than whites. African Americans are more likely to develop serious liver ailments such as hepatitis C, the chief cause of liver transplants. They are also more likely to die from liver disease, not because of any inherent racial susceptibility, but because blacks are less likely to receive aggressive treatment with drugs such as interferon or lifesaving liver transplants.

Even the legion of newest illnesses—emerging disease such as HIV/AIDS and hepatitis C—kills blacks at much higher rates than whites. AIDS, the scourge of our time, has become a disease of people of color here and abroad: Forty-nine percent of HIV-infected Americans are

African Americans and 86 percent of children with AIDS are African American or Hispanic. Blacks are ten times as likely to develop AIDS as whites.

Mental ailments are destroying blacks, as well: Black women suffer the highest rates of stress and major depression in the nation and suicide rates soared *200 percent* among young black men within just twenty years.

These are dire statistics, born of complex interactions among unhealthy environments, social pressures and limitations, lifestyle factors, and limited access to health care, including very limited access to cutting-edge *therapeutic* medical research that is meant to help treat or cure a patient with a disorder. But this dearth of therapeutic research is accompanied by a plethora of nontherapeutic research with African Americans, which is meant to investigate medical issues for the benefit of future patients or of medical knowledge.

And this brings us to the subject of this book, which documents a peculiar type of injustice in health: the troubled history of medical experimentation with African Americans—and the resulting behavioral fallout that causes researchers and African Americans to view each other through jaundiced eyes. In his 1909 preface to *The Doctor's Dilemma*, George Bernard Shaw scathingly observed, “The tragedy of illness at present is that it delivers you helplessly into the hands of a profession which you deeply mistrust.” He could have been speaking for contemporary African Americans, because studies and surveys repeatedly confirm that no other group as deeply mistrusts the American medical system, especially medical research.

The problem is growing. As the *Wall Street Journal* observed several years back, “It hasn’t been a good time for scientists who experiment on people—or the people they experiment on.” This is a masterpiece of understatement, especially if you consider the recent history of medical research with African Americans.

The Office for Protection from Research Risks (OPRR) has been busily investigating abuses at more than sixty research centers, including experimentation-related deaths at premier universities, from Columbia to California. Another important subset of human subject abuse has been

scientific fraud, wherein scientists from the University of South Carolina to MIT have also been found to have lied through falsified data or fictitious research agendas, often in the service of research that abused black Americans. Within recent years, the OPRR has also suspended research at such revered universities as Alabama, Pennsylvania, Duke, Yale, and even Johns Hopkins.

Many studies enrolled only or principally African Americans, although some included a smattering of Hispanics. Some research studies specifically excluded white subjects according to the terms of their official protocols, the federally required plans that detail how research studies are conducted. However, in other human medical experiments, the recruitment of blacks and the poor is a tacit feature of the study because they recruit subjects from heavily black inner-city areas that tend to surround American teaching hospitals. American university research centers have historically been located in inner-city areas, and accordingly, a disproportionate number of these abuses have involved experiments with African Americans.

These subjects were given experimental vaccines known to have unacceptably high lethality, were enrolled in experiments without their consent or knowledge, were subjected to surreptitious surgical and medical procedures while unconscious, injected with toxic substances, deliberately monitored rather than treated for deadly ailments, excluded from lifesaving treatments, or secretly farmed for sera or tissues that were used to perfect technologies such as infectious-disease tests. A few African American medical institutions have suffered their own run-ins with federal oversight agencies concerned about how they treated their own research subjects.

But the considerable concern raised by governmental oversight agencies has been dwarfed by the periodic hue and cry raised in the popular press. The news media seize upon and decry new experimental abuses with regularity. Moreover, it is newspapers, not research oversight organizations, that have been instrumental in unveiling and ending egregious abuses, from the Tuskegee Syphilis Study in the 1970s to the 1996 jailing of poor black mothers who were unwitting research subjects in South Carolina, to the 1998 infusion of poor black New York City boys with the cardiotoxic drug fenfluramine.

However, newspapers and magazines have given such abuses episodic rather than analytic treatment, expending their outrage, then falling silent until the next wave of research deaths, missing consent forms, or unwitting subjects steals headlines. Subjects are often identified not as black but, using coded references, as “the urban poor,” “socio-economically disadvantaged,” or “inner-city residents.” This episodic approach treats the exploitation of black experimental subjects as isolated events, so that even while the repeated reports buttress widespread distrust of medical research, these stories fail to discern the stubborn and illuminating *patterns* characterizing the medical abuse of African Americans.

In fact, the news media often fail to perceive unethical experimentation, even as they write about it. Scientists promulgate novel drugs and technologies, such as Norplant use among adolescents and psychosurgery for rioters, as new therapies that are necessarily extreme remedies. But despite the “treatments” ’ untried nature and the vulnerability of their subjects, the news media often swallow such euphemistic labels as “breakthrough” and “new therapy” whole.

Research is an utterly essential and desirable component of treatment, but its subjects must be aware that they are participating, must be informed, must consent, and must be allowed to weigh the possible risks and benefits. As this book will show, these conditions are only haphazardly met, or not at all, when the subjects are African Americans.

A Historical Vacuum

The experimental exploitation of African Americans is not an issue of the last decade or even the past few decades. Dangerous, involuntary, and nontherapeutic experimentation upon African Americans has been practiced widely and documented extensively at least since the eighteenth century.

Attempts to understand the distrust this history generates are confused and distorted because few know its facts beyond a few oft-cited experimental outrages, notably the Tuskegee Syphilis Study. History of medicine courses, medical museums, and even much medical scholarship leave one unaware of the long tragic history of medical research with

African Americans.

There *are* fine books that address more general issues in the history of African Americans in medicine. These include *The History of the Negro in Medicine*, by Herbert M. Morais; *Making a Place for Ourselves*, by Vanessa Northington Gamble, M.D.; and the sweepingly ambitious *An American Health Dilemma*, by Drs. Linda Clayton and Michael Byrd.

Other works deal with discrete instances of African American experimental exploitation, such as James Jones's *Bad Blood* and Susan M. Reverby's *Tuskegee's Truths. The Plutonium Files*, by Eileen Welsome, meticulously details government radiation experiments in a gripping exposé *Bones in the Basement*, by Robert Blakely and Judith Harrington, documents the archaeological evidence that revealed how the Medical College of Georgia used stolen African American bodies for physician training; Allen Hornblum's *Acres of Skin* chronicles experimentation in Philadelphia's Holmesburg prison complex; and *The Treatment*, by Martha Stephens, does the same with Cincinnati's radiation experiments. Most of the abuses detailed in these books targeted African Americans. *Killing the Black Body*, by Dorothy Roberts, includes research in its examination of the reproductive constraints on African American women in a historical context; and Sharla M. Fett's *Working Cures* and Todd L. Savitt's *Medicine and Slavery* are seminal histories of antebellum medicine that discuss research issues, but not exclusively.

A few scholars have devoted books to research with blacks abroad, such as Clarence Lusane's fine *Hitler's Black Victims*, Wolfgang U. Eckart's *Medizin und Kolonialimperialismus*, on medical colonialism in Germany's African holdings, and Jan-Bart Gewald's *Herero Heroes*, on the German medical abuse of Namibia's Herero people.

But none of the works listed above attempts anything like a comprehensive history of the racial research wars. There have been no inclusive treatments of African American medical research, and only a few books on discrete aspects of that history—focusing on research in a single prison, a single archaeological discovery of African American bones in a medical school basement, a single experiment with syphilitic men, or a single radiation experiment.

Why? “History is written by the victors,” warned Churchill, and a Nigerian proverb issues a similar caveat: “Don’t let the lion tell the giraffe’s story.” The history of medicine has been written by medical professionals and so reflects their points of view. The experimental suffering of black Americans has taken many forms: fear, profound deception, psychological trauma, pain, injection with deadly agents, disfigurement, crippling, chronic illness, undignified display, intractable pain, stolen fertility, and death. None reflect well upon their medical practitioners, so this experimental abuse often has been downplayed or misrepresented as “therapy” in the medical and popular literature. This book reveals these tendencies as well as the lack of objectivity and sensitivity with which African American fears are often greeted, and the social and cultural reasons for the lack of common ground.

The slave appropriated by physicians for experimental surgeries, the impoverished clinic patient operated upon to devise or demonstrate a surgical technique, the sharecropper whose body is spirited from the morgue for dissection, the young girl whose fertility is stolen via an untested contraceptive technique or a “Mississippi appendectomy” (involuntary sterilization), the soldiers, prisoners, and children who find themselves without options when government physicians foist novel medications and techniques upon those with little legal protection—all these African Americans, and many more, have found themselves voiceless as medical lions have chosen to present this research in a bowdlerized manner.

The oral histories of medical abuse voiced by African Americans are often dismissed as mythological, but without objective proof of this label. African Americans’ personal stories and familial histories of abuse have rarely surfaced in the medical literature, or in the popular literature. This is not surprising, because African Americans were not well represented in these canons until fairly recently.

Why should we give the physicians’ medical narratives more credence than the numerous contentions of slaves, sharecroppers, and contemporary African Americans that they have been subjected to abusive medical research? Until now, the discussion has suffered greatly from our Western literary bias, which encourages us to believe planters’ and physicians’ writings about the health and medical issues of African Americans, but to

give insufficient weight to a rich oral history passed down by African Americans, a history that has preserved the memory of medical abuses. We quite logically cede medical authority to medical experts, but this book will illustrate how race, culture, and economics have trumped medical and scientific truths at every turn. It will make the case that physicians had every motive to skew narratives against their black subjects, not because they were especially racist or unfair (although many were) but because the culture of American medicine has mirrored the larger culture that encompassed enslavement, segregation, and less dramatic forms of racial inequity. The bias against African American medical narratives emanates from culture and politics, including the Western literary bias against oral history.

Because slaves were forbidden to read, and segregated educational institutions perpetrated illiteracy and undereducation, black Americans' contributions to historical understanding of their role in American medicine were dwarfed or silenced. Finally, physicians' accounts carefully inculcated beliefs about black fearfulness, credulousness, emotional instability, and a tendency toward falsehoods that helped to discount claims of abuse.

The resulting lacunae in American medical history feed erroneous assumptions about blacks' medical wariness. An almost innate resistance to all medical research is ascribed to all African Americans. Often, the fear of becoming an abused, unwitting subject is laid to one signal instance of abuse, the Tuskegee Syphilis Study, rather than to a centuries-long history of such abuse.

Fortunately, the facts recorded by researchers and scientists themselves, in medical journals, texts, speeches, and memoirs, buttress African American claims for several reasons. Until three or four decades ago, these researchers were speaking only to their like-minded peers—other whites, usually male and rarely of the lower classes. They could afford to be frank. Blacks were barred from many medical schools and training programs, and newspaper and magazine reporters rarely read the medical publications perused by specially trained medical men of means. There was very little danger any blacks would read medical accounts, because in the antebellum period black literacy was banned by law and illiteracy persisted long beyond slavery. Therefore a doctor could be open about buying slaves for

experiments, or locating or moving hospitals to areas where blacks furnished bodies for experimentation and dissection. Public Health Service physician Thomas Murrell could brashly insist in the 1940s, “The future of the Negro lies more in the research laboratory than in the schools.... When diseased, he should be registered and forced to take treatment before he offers his diseased mind and body on the altar of academic and professional education.” Even more recently, the segregated nature of U.S. medical training emboldened some physicians to speak with candor of misusing black subjects. “[It was] cheaper to use Niggers than cats because they were everywhere and cheap experimental animals,” neurosurgeon Harry Bailey, M.D., reminisced in a 1960s speech he delivered while at Tulane Medical School.

But as societal attitudes changed, so did physician reticence, and most became more circumspect. However, as late as 1995, radiation scientist Clarence Lushbaugh, M.D., explained that he and his partner, Eugene Saenger, M.D., chose “slum” patients as radiation subjects because “these persons don’t have any money and they’re black and they’re poorly washed.” This book will document numerous instances of such shocking frankness on the part of white researchers and physicians when they thought that nobody outside of their peer group was listening.

In the course of explaining what constitutes exploitative experimentation, *Medical Apartheid* will explain the meaning and nature of informed consent and the differences between therapeutic and nontherapeutic research. It traces the delicate balance between experimental risk and benefit because symbiosis, not complete freedom from harm, is the therapeutic goal, a goal that often eludes African Americans. The individual chapters also supply general background on how experimental practices evolved over the periods covered in this book and how laws and institutional review boards now protect volunteers, albeit still imperfectly.

Finding the Truth in Plain Sight

It is medical researchers themselves who have documented the proof of this long, unhappy history of African Americans as research subjects. Even so, this history has been a challenge to document because it has been

hidden in plain sight—widely scattered, distorted, and rendered all but unrecognizable as abuse by heavy editorializing. As I recall the years I have spent ferreting out these experiments bit by bit, examining their patterns, and probing the mind-sets that they revealed, I am put in mind of the legal discovery process. A favored ploy is to provide the opposing side with all the information it seeks—buried in towering mountains of unrelated or tangentially related documents. Similarly, I have perused dusty antebellum medical journals, the Surgeon’s General’s Index, its successor, the Medline database, physicians’ memoirs and literary efforts, slave narratives, and painfully picked my way through foreign publications in alien tongues that are sometimes more forthcoming than domestic publications about the history of our medical treatment of minority groups. Mining the bright but thin lodes within these resources, I gradually amassed a cache of evidence.

As previously hidden experimental exploits come to light, some have challenged the characterization of such research as “secret,” noting that the reports were published in medical and scientific journals that could be read by anyone. But these critics would do well to weigh Marcel Pagnol’s definition of secrecy: “A secret is not something unrevealed, but told privately in a whisper.” Until the past few decades, descriptions in medical publications of experimentation with African Americans were shielded from the eyes of the uninitiated. Generalized professional journals such as the *Journal of the American Medical Association* and *The New England Journal of Medicine* are not available in bookstores or on newsstands. Specialized medical journals are even less accessible, and access was even more restricted in past decades. The medical libraries that house these journals have historically been closed to the public and most remain so; indeed, I have been challenged while entering such libraries while a student or instructor at various northern universities. Moreover, physical access to such journals would constitute only the first hurdle: The medical jargon in which such research papers are couched is often impenetrable even to well-educated nonmedical people.

But some of the people central to medical research have been more generous with their knowledge. Scores of researchers, physicians, and research subjects have shared their time and expertise and added depth to my understanding of the cultural divergence that has fed this history. Often, they told me more than they realized.