

PART 3 Race, Technology, and Medicine

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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 shock-

ing 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, al-

though 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," "socioeconomically 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 ex-

posé; *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, Eu-

gene 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.

For example, a duality has persisted, as I have learned from them more than the facts of scientifically questionable and ethically troubled medical research. Whether we were discussing the etiology of tuberculosis, gynecological surgery, or the implication of census health statistics, these sources have conveyed to me Rorschach-like, divergent medical worldviews. The overarching presence of two Americas, one healthy and white and the other filled with sick, disaffected people of color, has haunted our discussions.

Scientists who abuse, exploit, and lie to research subjects get more than their share of ink, but I have spent enough time among physician-scientists to believe that most American researchers, white and black, are idealistic and skilled. However, when it comes to the abuse of African Americans, a different set of ethical standards has long prevailed and abusive researchers have historically been closer to the norm than we would like to think. Conventional wisdom pins experimental abuses on the "Dr. Frankenstein" stereotype—a scientific outcast of dubious pedi-

gree who harbors blatant social or mental maladjustment. But, historically, most perpetrators of ethically troubling experiments utilizing African Americans have been overachieving adepts with sterling reputations, impressive credentials, and social skills sufficient to secure positions of great responsibility. The stereotype of the abusive researcher as a coolly amoral renegade is a stock figure borrowed by journalism from science fiction: Like all stereotypes, it is one-dimensional and therefore false. Professionally and socially, these rogue stars have much more in common with the top strata of other successful American researchers than they do with mythical madmen.

In fact, researchers who exploit African Americans *were* the norm for much of our nation's history, when black patients were commonly regarded as fit subjects for nonconsensual, nontherapeutic research. This book explores the many reasons that blacks are so vulnerable, but ultimately it is because American medical researchers remain a racially homogeneous group, and I show how the racial homogeneity of American medical researchers lies at the very heart of the problem.

The Curious World of Medical Research

Ironically, my interest in medical research using African Americans is a direct outgrowth of my long-standing fascination with the more noble history of medicine. In fact, when asked to describe my work, I usually explain that I am a medical voyeur. I am an admirer of medicine, and, when not working alongside physicians in hospitals, I have spent decades profiling, describing, and analyzing medical advances and the remarkable people who make them. In my many magazine and newspaper articles and in books that celebrate modern medical innovation, I have tried to convey the achievement, mission, and wonder of healers; my greatest challenge has usually been to avoid descending into frank hagiography. This admiration began at age eight, when Albert Schweitzer's *Out of My Life and Thought* became my favorite book, but it crystallized while I was an undergraduate at the University of Rochester.

My favorite floor of the undergraduate library housed physicians' memoirs of a medical swashbuckler genre that included such titles as *My Patients Were Zulus* and *Burma Doctor*. These heroic reminiscences of lands populated by African and Asians mingled adventure with medical

proselytizing and constituted a guilty pleasure for me as I pored over them when I should have been reading the assigned Chaucer or genetics. These readings also constituted a guilty pleasure because, although I originally read them as accounts of selfless physicians who cared for people of color, I soon realized that these accounts reeked of xenophobia. Most were deeply disdainful of the natives on whom physicians bestowed the blessings of Western medicine and Western civilization. Because these exploits were distant in time as well as geography, I was less critical than I should have been when they sneered at the ignorant customs of superstitious natives. It all happened so long ago, I thought: surely those colonial attitudes were dead now. I even made excuses for doctors whose disdainful observations were sprinkled with ethnic slurs, or when they congratulated themselves for conducting dramatic, not always benign, experiments upon the unwitting, I excused them on the basis that all this had taken place in the unenlightened past: How could we judge them for abuses conducted under the aegis of yesterday's morals? As the years passed, this became a progressively unsatisfying rationalization, and I eventually abandoned my medical adventurers.

Some years later, I opened a drawer and lost the remains of my innocence. I was running a modest poison-control center in a teaching hospital in upstate New York, and we poor toxicologic relations had expanded into a space that had been reluctantly yielded us by Radiology, a "real" medical department. When I opened a recalcitrant drawer of a file cabinet that had been left behind, a few forgotten medical folders from the 1970s littered its bottom. One contained the file of an older gentleman in imminent kidney failure and focused upon documenting the reams of tests and assessments entailed in finding him a matching kidney for transplant. The social history stressed his loving family and determination to live. Another file also described the plight of an older man in kidney failure, but it looked different, thinner. The first page I read documented his odyssey into sickness as his kidneys failed. It noted among other things that he was retired, insured, and "Negro." Nearly every page recorded his race and someone had underlined it on his social profile, just above the line that indicated that the medical staff's plans for him were not to secure a transplant but to help him to "prepare for his imminent demise." It was signed by a kind, erudite physician I knew and admired and who had actively encouraged my interest in medicine. I could not reconcile this signature with the man I knew, a sensi-

tive scholar and devout Christian. Probably, I thought, I was jumping to conclusions and the patient's race had nothing to do with his failure to be considered for a lifesaving organ.

When I haltingly voiced my fears to an African American acquaintance who had worked as a ward clerk in the nephrology unit, she looked at me as if I were not too bright and minced no words. "Girl, black people don't *get* organs; they *give* organs." During our ensuing debate, she pointed out to me that the race bias in the hospital where we worked should have resolved any doubts: In the early 1980s, most of its black employees worked in housekeeping and clerical support. Blacks were noticeably scarce among the administrative and medical staffs. Why, she asked, was I naïve enough to believe racial bias stopped at the staffing roster?

This was hardly proof, but my discomfort grew as she categorized instance after instance of overt bias and finally declared, "I would never have a procedure done here: I've seen too much. To them, if you're black and poor, you're nothing but a guinea pig." I realized that my discomfort with her words went beyond the truth or falsity of her allegations: The mere fact that she believed them was unsettling, because she had worked in a hospital setting, was presumably better informed than most, yet she did not trust the medical system and seemed less likely to turn to it when ill. The perception of evil in such cases, I realized, can prove as damaging as malfeasance itself.

I finally glimpsed that understanding the true extent of unethical medical research with African Americans was more than idle curiosity or an academic exercise: It was key to removing barriers between African Americans and the bounty of the American health-care system.

In the hospital's medical library, I discovered a new genre of physician confessional literature, one that described black patients not in Africa but here in the United States. Unlike the African book-length exploits, these often consisted of a revealing passage or two in an autobiography, a few pages in a memoir, or a hoary article in a nineteenth-century medical journal. I recognized in these Western accounts of black American patients the very same stereotypes belabored in African accounts.

References in American physicians' memoirs and journal articles were studded with telling vignettes and observations of their black patients. The stories physicians told mixed stereotyped comedy with exasperation as they dismissed blacks as disease-ridden, unintelligent,

fearful, distrustful, and, above all, "noncompliant" patients. By "noncompliant," doctors meant patients who could not be trusted to follow medical advice or even to act intelligently in their own best medical interests. I realized that such negative presumptions hampered physicians' ability to care for black patients or even to see them as worthy of the same excellent care rendered to others.

For their part, the black patients I met and interviewed shared their own medical lore, which warned against trusting Western medical practices and physicians, a matrix they characterized as racist, rapacious, and eager to exploit black bodies for medical gain at the cost of health. Thus the disparate narratives African Americans and physicians tell unveil a state of undeclared war or, at best, an uneasy truce between physicians and their black patients.

But I knew that analyzing the history of African Americans as research subjects would necessitate more than a familiarity with history and contemporary medical literature; a sound understanding of basic medical sciences and medical cultures, regulations, protocols, research design, and procedures would also be necessary. This would require a research plan enabling me to ferret out studies in a wide variety of disciplines and subjects. Finally, I would have to speak to medical researchers, subjects, and patients about sensitive experiences. At that time, around 1980, data on racial health disparities was sparse and anecdotal, and in any event, I felt unqualified to take on such a daunting task. I had some grounding in the basic medical sciences, but having abandoned my premedical studies, my knowledge was incomplete. However, I occupied a good vantage point from which to observe and accrue an understanding of medical research culture. I had worked in hospitals for a decade, in positions ranging from ward clerk to laboratory technician to department manager and in venues ranging from the animal laboratory to the cancer-research laboratories to the psychiatric emergency department to the poison-control center. The physicians for whom I worked openly discussed their work with me and were more forthcoming with me as a lowly clerk or technician than they would have been with a journalist.

I eventually left the hospital to work as an inner-city medical social worker ensconced in settings where I constantly talked to African American clients and their caregivers about their beliefs and behaviors concerning medical care and research.

I then worked as a journalist, most notably as a news editor and science editor at daily metropolitan newspapers for seven years, including a brief stint at *USA Today*. After that, I worked as a medical journalist, a columnist, and a contributing editor for several national magazines. My work was published by the New York Times Syndicate and appeared in popular publications as diverse as *Health*, *USA Today*, *Essence*, and *Psychology Today*. I was also published in academic publications such as the *Harvard Public Health Review*, *Nature*, and the *American Journal of Public Health*, and I edited the *Harvard Journal of Minority Public Health*, an especially valuable experience. A monthly medical column that I wrote for *Emerge* magazine gave me experience in framing the issues this book explores for a general audience, and it opened a conduit for numerous first-person testimonies as well.

On a parallel track, I obtained a firm scientific background by completing a premedical course and medical school courses in immunology, toxicology, and neuroscience. As I took classes with medical and doctoral students and postdocs, they became my best sources by relating contemporary research they had participated in. Often they confessed to being troubled by ethical concerns, and this validated my anxiety about some disquieting trends in the commercialization of medical care and in what I increasingly perceived as an erosion of informed consent to research.

Academic institutions, including Stanford, Maryland, and the Medical University of Lübeck, invited me to share with their scholars what I was learning about the hidden history of experimentation with African Americans. At the same time, I embarked upon a Harvard Medical School Fellowship in Medical Ethics. We addressed thorny issues in the philosophy and policy of medical research and engaged in a wealth of readings seminars with important experts. But it is my own assessments of these studies, informed by my medical ethics training, that form the basis of the ethical analyses in this work. They stand or fall on my own logic and historical knowledge.

The Scope and Structure of *Medical Apartheid*

I was determined that *Medical Apartheid* not be a simplistic "black hats, white hats" story in which African Americans are passive victims and researchers are always villains. Instead, the book takes a frank but more

nuanced look at the calculus of racism's effects on experimental practice. I have attempted to write a social history that traces the key role that various researchers have played in both promulgating and refuting racism in medicine.

It was impossible and undesirable to incorporate every instance of racialized experimental abuse that I unearthed: This would have resulted in a long, dreary checklist of horrors and little useful insight. The bulk of questionable experimentation upon African Americans is not detailed here because much of it consists of aberrations in therapeutics that were ostensibly meant to cure. Attempts to heal that transgress against ethical rules by dramatically escalating dosages and techniques or that involve nonmaterial breaches of consent are still wrong and risky, but they concern me less because they are sometimes products of honest error and because the intent is still to heal or help. This book focuses more heavily upon experiments with mammoth risks, little or no therapeutic content, or no possible benefit to the subjects, and upon mere attempts at exploitation to perfect medications, procedures, and techniques.

Therefore, this book is not a complete chronology of abusive racial research; rather, it is a thematically organized collection of historical and contemporary issues in medical research with African Americans, illustrated by important cases. I also broach a discussion of such previously ignored historical themes as the fact that fraud is often a traveling partner of racially abusive research. I also explore the history of using African Americans in experimentation intended to support unflattering racial stereotypes and beliefs. African Americans have been used, for example, to perfect the IQ tests that would "prove" them inferior in intelligence, to devise the treponemal tests that would prove them ridden with a distinctive strain of syphilis, and to perform the painful skin and visceral dissection that would prove that "blackness," or negritude, is a permanent mark of biological inferiority that exists independent of skin color.

Some other important medical issues have been excluded from this work because they spill outside the strictest thematic boundaries of African Americans in medical research.

Despite the long and rich history of medical abuse in African and other Third World countries, much of it conducted by U.S. researchers, there is no chapter detailing such research in this book. In one sense, this is akin to discussing Jewish issues without discussing Israel, but the

sweeping history of such research is far too extensive to address in a single chapter, especially because it is burgeoning rather than abating.

Similarly, it is impossible to capture completely the important work of African American medical researchers in a single chapter, and I have reluctantly deferred a discussion of this neglected subject both for space reasons and because black researchers have tended to engage in therapeutic research rather than in the troubled investigations that are the subject of this work.

Medical Apartheid consists of fifteen chapters organized into three parts. Part 1, "A Troubling Tradition," takes a chronological approach to the role of African Americans in early American medicine. It stresses the experimental abuse and exploitation of African Americans from the first encounters in the New World through the post-Civil War era and then up until the Tuskegee Syphilis Study, which began in 1932.

Part 2, "The Usual Subjects," covers the period from the early twentieth century to the present day in a roughly chronological manner. However, it departs from strict chronology in favor of an analysis of specific types of vulnerable subjects—children, soldiers, and hospital patients—used in research conducted by institutions ranging from the federal government to private corporations.

Part 3, "Race, Technology, and Medicine," examines contemporary research issues, including genetic research, investigations into emerging diseases, and bioterrorism.

In the epilogue, "Medical Research with Blacks Today," I discuss how the worst abuses have been replaced by more subtle threats to the rights of the individual to choose whether and when to participate in medical research.

Finally, the appendix directs readers to a wealth of guidelines and regulations to help them navigate clinical trials.

Why Research Issues Still Matter

Why do centuries of mutual distrust over medical research matter today? What does the sad history of exploitative experimentation augur for black health?

"What the French see in wine, Americans see in health care," mused Robert J. Blendon, Ph.D., professor of Health Policy and Political Analy-

sis at the Harvard School of Public Health. Americans consider access to excellent health—and even the most expensive means of maintaining it—their birthright. Americans enjoy ever-burgeoning longevity, extravagant nutrition, and everyday access to superb medical care, including expensive high-technology interventions. From CAT scans on demand to new hips to keep us on the tennis courts and new hearts to keep us in the game, we demand the best care, including novel and experimental therapies. Our devotion to the very latest in expensive remedies for increasingly marginal medical gains has many Americans bumping up against the law of diminishing returns.

At the same time, medical experts of every persuasion agree that African Americans share the most deplorable health profile in the nation by far, one that resembles that of Third World countries. When Dr. Harold Freedman observed that the health status of Harlem men resembles that of Bangladeshis more closely than that of their Manhattan neighbors, he did not exaggerate. Twice as many African American babies as babies of other ethnic groups die before their first birthday. One and half times as many African American adults as white adults die every year. Blacks have dramatically higher rates of nearly every cancer, of AIDS, of heart disease, of diabetes, of liver disease, of infectious diseases, and they even suffer from higher rates of accidental death, homicide, and mental illness. Before they die young in droves from eminently preventable diseases, African Americans also suffer far more devastating but equally preventable disease complications, such as blindness, confinement to wheelchairs, and limb loss. Studies continue to demonstrate that, far from sharing in the bounty of American medical technology, African Americans are often bereft of high-technology care, even for life-threatening conditions such as heart disease.

The much bewailed racial health gap is not a gap, but a chasm wider and deeper than a mass grave. This gulf has riven our nation so dramatically that it appears as if we were considering the health profiles of people in two different countries—a medical *apartheid*. Researchers have proffered a cornucopia of theories for this medical divide, many of which focus upon putative biological dimorphisms, especially genetic differences.

But in dissecting this shameful medical apartheid, an important cause is usually neglected: the history of ethically flawed medical exper-

imentation with African Americans. Such research has played a pivotal role in forging the fear of medicine that helps perpetuate our nation's racial health gulf. Historically, African Americans have been subjected to exploitative, abusive involuntary experimentation at a rate far higher than other ethnic groups. Thus, although the heightened African American wariness of medical research and institutions reflects a situational hypervigilance, it is neither a *baseless* fear of harm nor a fear of imaginary harms. A "paranoid" label is often affixed to blacks who are wary of participating in medical research. However, not only is *paranoid* a misnomer but it is also symbolic of a dangerous misunderstanding. That is why I refer to African American fears of medical professionals and institutions as iatrophobia, coined from the Greek words *iatros* ("healer") and *phobia* ("fear"). Black iatrophobia is the fear of medicine.

Even those who investigate the role of medical ethics and medical policy are trying to dissect and analyze the much decried African American aversion to medical research without understanding the history that created that aversion. The historical cause of the racial health gap has been only crudely and cursorily examined and is usually reduced to knee-jerk responses to the Tuskegee Syphilis Study, as if this were the only instance of problematic medical experimentation. But scores of historical events connected with medical research have plagued black Americans and affected their health-seeking behavior. This historical silence is a grave omission, because trying to ameliorate African American health without understanding the pertinent history of medical care is like trying to treat a patient without eliciting a thorough medical history: a hazardous, and probably futile, approach.

Kill the Messenger

In fact, some otherwise well-meaning people wish to censor any analysis of troubled research with African Americans, as I discovered firsthand, to my great surprise. I was elated when a professor at a U.S. medical school summoned me to her office, explaining that she wanted to hear all about the book I was writing. Ensnared in a chair, I eagerly began to describe my work, only to be cut off before I had completed the first sentence. Bolting upright in her chair, she vehemently informed me that the topic of this book was taboo. "It's a terrible thing that you are doing. You are go-

ing to make African Americans afraid of medical research and physicians! You cannot write this book!" As she glared at me, her face became contorted with anger, suffused with blood, and her breathing grew rapid. For a moment, I was stunned into silence, because nothing had prepared me for her reaction. After all, freedom of speech and academic freedom are sacred in this country. I was also a bit surprised that a white academic whose discussions and syllabus had evinced no interest or expertise in the matter should lecture me, an experienced African American medical writer, about health communication with African Americans.

She proceeded to inform me that there had been no medical research utilizing African Americans before the Tuskegee Syphilis Study, certainly not in the antebellum past, and when I asked her how she knew this, she countered, "Can you prove that there was?"

When I responded simply, "Yes," she disgorged a clumsy inquisition, unleashing a barrage of questions that showed she knew nothing about the subject at hand. I responded that my work was well researched and that she had raised an interesting question: Was it indeed my work that would make African Americans wary of health care and medical research? Or had the work of those whose abuses I proposed to chronicle already achieved this? The answer was all too obvious: I knew from years as a medical social worker, a medical journalist, and a researcher that black Americans did not need me or anyone else to inculcate a fear of medicine. Medical history and practices had long since done so. *Medical Apartheid* is my attempt to document—at long last and as fully as possible—how and why this has happened.

PART 1 A TROUBLING TRADITION