



ESSAYS ON SCIENCE AND SOCIETY

Uses and Abuses of Tuskegee

The Tuskegee syphilis study has come to symbolize the most egregious abuse of authority on the part of medical researchers. Tuskegee has also come to serve as a point of reference for African Americans distrustful of those with power, emblematic of the history of a people enslaved and then subject to social, legal, and political oppression after the end of formal servitude. When Tuskegee as a symbol of research abuse and racial oppression are merged, a potent device is at hand for uncovering profound social injustice (1). When, however, the legacy of Tuskegee is incautiously invoked, it can serve to make consideration of complex matters involving research with socially vulnerable people all but impossible.

To understand both the uses and abuses of Tuskegee requires that we understand the story of what happened in rural Alabama between 1932 and 1972. As part of its study of the long-term effects of syphilis, the United States Public Health Service (PHS) denied treatment to 399 poor African American men suffering from the tertiary effects of the disease. Researchers and physicians involved in Tuskegee chose not to inform the study's participants that they were infected with syphilis or educate them regarding its treatment or prevention. Rather, they lured men to the study by offering free treatment for "bad blood"—a generic term that referred to a variety of ailments. The PHS thwarted all efforts the men made to receive treatment from other sources. When penicillin dramatically altered the treatment of syphilis in the 1940s, the PHS withheld it, arguing that never again would they find such a group of untreated individuals (2).



Remorse. President Clinton apologized to the victims of the Tuskegee syphilis study 16 May 1997.

Although Tuskegee was a study that the PHS adapted to changing circumstances, it is possible to derive three features that characterize the consistent research abuses that occurred. First, the study involved deceptions regarding the very existence and nature of the inquiry into which individuals were lured. As such, it deprived those seeking care of the right to choose whether or not to serve as research subjects. Second, it entailed an exploitation of social vulnerability to recruit and retain research subjects. Third, Tuskegee researchers made a willful effort to deprive subjects of access to appropriate and available medical care as a way of furthering the study's goals.

Thus viewed, Tuskegee touched on issues central to research ethics and can serve as a standard against which to judge contemporary examples of research abuse. But, as a historical event involving the exploitation of African Americans that entailed the examination of a racist thesis, the legacy of Tuskegee and the outrage it has spawned is suffused with race. Within weeks of the first news reports of Tuskegee, the African American press and African American political leaders began to view a host of medical and public policy issues through the lens of Tuskegee (3). "Tuskegee," which quickly became a metaphor for genocide, crystallized a history of medical neglect and abuse that was a consequence of social and political disempowerment (4). In this article, we examine the uses and abuses of Tuskegee in three highly visible AIDS-related debates, which spanned the past decade.

Needle exchange. The provision of sterile injection equipment to intravenous drug users has been proposed as a way of interrupting the spread of HIV infection since the mid-1980s (5). Wherever needle exchange programs emerged, African American leadership gave voice to their dismay and fury, rooted in suspicions that the failure to provide adequate treatment to drug users represented a form of genocidal neglect (6).



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In New York City, because of political opposition to needle exchange from both law enforcement proponents and the African American community, the city's health commissioner was compelled to present his 1988 needle exchange effort as a small experiment designed to determine whether such a radical innovation could reduce the incidence of infection among drug users without encouraging drug use (7). Ironically, the very political cover that the experiment was designed to provide set the stage for the charge of "Tuskegee." In denouncing the experiment, Benjamin Ward, the City's African American Police Commissioner, alluded to the Tuskegee syphilis trials when he explained that his community felt "a particular sensitivity to doctors conducting experiments, and they too frequently seem to be conducted against blacks" (8). Reverend Reginald Williams echoed his sentiments, combining the imagery of Tuskegee and genocide: "Why," he demanded, "must we again be the guinea pigs in this genocidal mentality?" (9).

When David Dinkins, long opposed to needle exchange, became the city's first African American mayor, he almost immediately ended the trial. Yet by the mid-1990s, the intense African American opposition to needle exchange had all but vanished—eroded by the apparent effectiveness of such

CREDIT: (LEFT) DOUG MILLS/AP; (RIGHT) ALLAN BURCH

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efforts and by the fragmentation of opinion among African American leaders. As Tuskegee ceased to serve as a tool for critics of needle exchange it increasingly became a symbol for the advocates of such efforts. It was in this context that a furious debate emerged when the NIH funded a clinical trial in Anchorage, Alaska, to determine whether over-the-counter sale of injection equipment—a practice permitted in Alaska but prohibited in many jurisdictions with serious drug problems—was more effective than formal needle exchange programs.

In October 1996, Peter Lurie and Sidney Wolfe, physicians at Ralph Nader's Public Citizen's Health Research Group, sharply attacked the \$2.4 million study. They charged that the study was "deceptive" in failing to inform participants of the relative benefits of the needle exchange and that it "actively prevented" [those assigned to the pharmacy arm] from obtaining access to clean needles through the needle exchange" (10). Equally troubling, one of the study's measures of efficacy—the incidence of hepatitis B infection—was utterly preventable by a vaccine. Lurie and Wolfe concluded, "The parallels here to the Tuskegee Syphilis Study ... are clear" (11). In an unprecedented reaction, NIH director Harold Varmus suspended the study pending review by an outside committee, which concluded that the study was no Tuskegee, describing the critique of the study as "misunderstanding, mischaracterization, or both" (12).

With the study set to move forward, bioethicists Arthur Caplan and George Annas continued the attack, maintaining that the study amounted to allowing researchers to "stand by and observe as their subjects develop devastating diseases that could be prevented." "This," they continued, "is the lesson learned in the notorious Tuskegee syphilis study.... It is not ethically acceptable to learn from the misery of the vulnerable without protecting them from known risks of serious harm" (13).

Both iterations of the needle exchange debate revolved around pressing questions of fairness in dealing with vulnerable populations. However, the charge of the Tuskegee-like abuse of research subjects was inappropriate in each instance. The failure to provide adequate treatment options for drug addiction, central to the complaint of African American opponents of needle exchange, most certainly represents tragic neglect and an example of gross inequity. But not all injustices are the equivalent of those represented by Tuskegee. Whereas in Tuskegee the PHS used the social circumstances of poor African American men to manipulate them into a study that would deprive them of treatment, proposals to provide sterile injection

equipment seek to address the vulnerable situation of those exposed to HIV by offering a potentially life-saving intervention.

Strong as is the evidence for the relative efficacy of needle exchange, the failure to establish such programs also does not constitute Tuskegee-like abuse. Those who were to be enrolled in the Alaska study would not suffer covert manipulation designed to deprive individuals of access to potentially effective care. Only insofar as the original study failed to offer hepatitis B vaccination to participants did it arguably

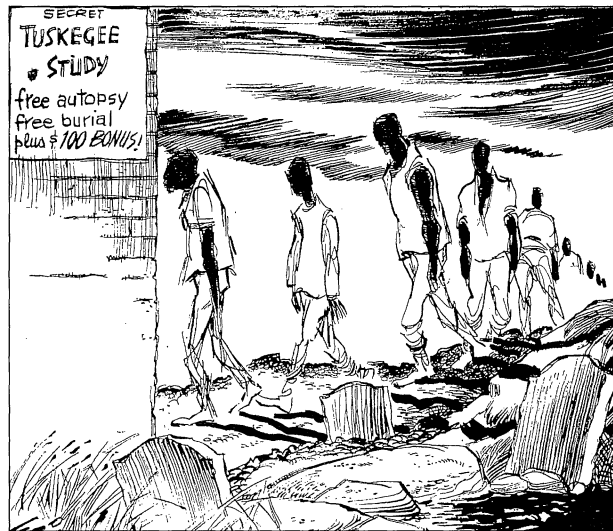
that when she first learned of the CDC studies in May 1993, she "was just so astounded. This was the Tuskegee experiment all over again" (16).

Arthur Amman, a professor of pediatrics at the University of California and head of the Pediatric AIDS Research Foundation, echoed her view. "The maintenance of anonymous test results at a time when treatment and prevention are readily available," he observed, "will be recorded in history as analogous to the Tuskegee 'experiment'" (17, 18). But unlike Mayersohn, he opposed mandatory testing.

On a federal level, Mayersohn's challenge was mirrored by Congressional Representative Gary Ackerman. In May 1995 he unveiled legislation to unblind the CDC newborn seroprevalence study (18). For Ackerman, it was simply unacceptable that unconsented testing continue in a context precluding notification (19). His Newborn Infant HIV Notification Act carried the support of 220 House members, including 31 members of the Congressional Black Caucus, some of who withdrew their endorsement as the question of mandatory testing came to dominate.

Speaking before the House Commerce Committee, Ackerman warned, "There was one point in our society, a very dark day when people were allowed to walk around after being tested with a dread disease just so the medical establishment could...see what happens..." (20). In response to the broad support behind Ackerman's Newborn Infant HIV Notification Act, the CDC—opposed to mandatory testing—preempted Ackerman's proposal and announced it would suspend the newborn serosurvey, effective 12 May 1995. Ackerman angrily alleged that the CDC was driven by the simple desire to avoid the taint of Tuskegee (21).

Changing therapeutic prospects appeared to alter radically the context of blinded testing, lending credibility to the charges of "Tuskegee." However, neither the CDC nor state public health departments engaged in blinded testing made efforts to deprive individuals of the opportunity for voluntary testing. Nor was there an effort to divert women who sought diagnostic testing from treatment for themselves or their infants. The very purpose of the studies was to identify populations at increased risk for HIV so that efforts to



Editorial comment. Cartoon from 27 July 1972, *The Atlanta Constitution*.

involve an ethical lapse—a lapse addressed by the NIH despite the recommendations of its ethical review panel. But that lapse, in and of itself, did not constitute the kind of abuse represented by Tuskegee.

Blinded seroprevalence studies. Beginning in 1988, health departments, with the support from the U.S. Centers for Disease Control and Prevention (CDC), conducted studies of HIV infection in the population by testing blood samples, stripped of all personal identifiers. When subject to ethical review, experts deemed such screening unproblematic (14). As it involved samples of blood, not identifiable individuals, informed consent was considered unnecessary (15). However, anonymization precluded notification of infected individuals.

As early clinical intervention became the standard of care, these studies came under attack. Notably, it was only those studies involving women and infants that drew the critical challenge. Nettie Mayersohn, a democratic representative in the New York State Assembly who believed infected babies—most of whom were the children of poor, minority women—had a right to testing and treatment. She therefore advocated mandatory newborn testing. She explained

identify individuals in need of care could be given the greatest priority.

Third World HIV Prevention Trials. In February 1994, the Data Safety and Monitoring Board of the U.S. National Institute of Allergies and Infectious Diseases interrupted AIDS Clinical Trial Group (ACTG) Study 076 (22). The preliminary data revealed a statistically significant and dramatic difference in vertical HIV transmission rates from mothers to their newborns, between women who received the active regimen and the placebo group.

The regimen quickly became the standard of care in industrialized nations, where no trial that would deny access to the ACTG 076 regimen or to a potentially equivalent intervention would satisfy the requirements of ethical review. In developing countries, however, the costs of the 076 regimen (\$800 for the drug alone) put it out of reach. It was, therefore, a matter of some urgency that trials begin to determine whether radically cheaper alternatives could reduce maternal-fetal HIV transmission. The CDC and NIH launched nine placebo-controlled trials, all subject to careful ethical review, in developing countries.

Nevertheless, on 18 September 1997, Marcia Angell, executive editor of the *New England Journal of Medicine*, denounced the placebo-control trials in Africa, Asia, and the Caribbean. Citing the Declaration of Helsinki for authority, she noted that control groups had to be provided with the best current therapy, not simply that which was available locally. Taking her lead from Lurie and Wolfe, who first drew the comparison to Tuskegee in regard to the Third World studies as they had in Alaska, she argued, "The justifications are reminiscent of those for the Tuskegee study: Women in the Third World would not receive antiretroviral treatment anyway, so the investigators are simply observing what would happen to the subject's infants if there were no study."

However problematic the efforts to obtain informed consent in the Third World, investigators clearly made efforts to inform the enrolled women that they would be part of a study to reduce maternal transmission of HIV and that some would receive a placebo. No attempt was made to exploit the social vulnerability of the women involved. Indeed, it was the very poverty of the nations within which these women lived that served as the predicate for the challenged studies. Only to the extent that these women could be said to have a realizable claim on the care available in industrialized nations would the conduct of a placebo control trial have mirrored the deprivation of Tuskegee. But then any trial to find a cheaper and potentially less effective regimen—whether placebo controlled or

not—would have been unethical as well. To the extent that the search for a less costly and potentially less effective intervention could be justified by the desperate need to find affordable interventions, the analogy to Tuskegee entailed a gross distortion.

Yet to the extent that women in poor countries have a moral—as contrasted with a realizable—claim on the care available to women in industrialized nations, critics helped to underscore the profound injustice that characterizes the world distribution of medical resources. Unfortunately, the invocation of Tuskegee launched a furious methodological debate that diverted attention from an analysis of the very poverty and inequality that necessitated the challenged studies.

Conclusion. When we understand Tuskegee as emblematic of a history of racism and the experience of social, economic, and political disempowerment, its legacy does much to explain the atmosphere of mistrust that surrounds research, especially when the subjects of study are poor, vulnerable, and are the potential targets of exploitation. That legacy is especially helpful in explaining the profound suspicions expressed by African Americans when the prospects of medical experimentation present themselves. Thus understood, Tuskegee underscores the importance of carefully and sensitively seeking to establish trust where it is absent or where historical experience has shattered it. As important, Tuskegee can draw our attention to the inevitable moral challenges that will emerge when research involves those who are socially vulnerable.

But for Tuskegee to serve as a useful analogy for illuminating research abuse, the challenged study must meet some reasonable, general criteria. It must involve deception regarding the nature and very existence of the research study, it must capitalize on social deprivation or vulnerability, and not only must it fail to provide the best available effective therapy but it must also contrive to keep individuals from receiving such therapy.

The past decade has demonstrated that the charge of "Tuskegee" is extremely effective in riveting public attention, but just as research demands of its practitioners that they adhere to standards of moral responsibility, challenges to research carry with them certain moral obligations. Those who would use Tuskegee to indict research efforts bear responsibility for how they deploy the legacy of that awful historical episode.

While Tuskegee can stimulate productive reflection on questions of social justice, its reckless invocation risks derailing serious and sustained discussion of the dilemmas posed by research with vulnerable populations. Ironically, it can also make current research abuses pale in comparison to the

historical syphilis study, thus minimizing their gravity. The abuse of Tuskegee has consequences not only for present discussion, but also for the past. It threatens to rob Tuskegee of its unique value and meaning. It misuses the memory of the 399 African American men whose most basic rights were violated for 40 years. In so doing, it diminishes the significance of their suffering.

References

1. D. L. Kirp, *Tikkun* 10, 3 (May 1995); D. J. Rothman, *The Hastings Cent. Rep.*, 5 (April 1982).
2. J. H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (The Free Press, New York, 1981, 1993).
3. "Black Babies Used as Guinea Pigs in Dangerous Research," *Amsterdam News*, 31 March 1973, p. A-2; W. Moore, "'Guinea Pig' Experiments are Conducted in Prisons," *Jet* 24 (August 1972), p. 20; "Blacks as Guinea Pigs," *Amsterdam News*, 27 January 1973, p. A-5; F. E. Ruffin, *Essence* (September 1972); Al Rutledge, *ibid.*, p. 42 (September 1973); D. Alexander, *Essence*, (September 1973); "Black Psychologists to Present Genocide Petition to UN," *Amsterdam News*, 3 September 1975.
4. J. H. Jones, *Hastings Cent. Rep.* 22, 38 (November 1992).
5. D. Sencer, "Choosing Between Two Killers," *New York Times*, 15 September 1985, World Health Organization, *AIDS Among Drug Abusers* (WHO Regional Office for Europe, Copenhagen, 1987); National Academy of Sciences, Institute of Medicine, *Confronting AIDS: Directions for Public Health, Health Care, and Research* (National Academy Press, Washington, D.C., 1986).
6. D. L. Kirp and R. Bayer, *The Atlantic* (July 1993).
7. H. L. Dalton, *Daedalus* (Summer 1989); W. Anderson, *Am. J. Public Health* 81, 1506 (November 1991); S. Thomas and S. Quinn, *J. Public Health Policy* 14, 320 (1993).
8. B. Lambert, *New York Times* (13 Nov 1988).
9. M. Marriott, quoted in (7), p. 210.
10. Letter from P. Lurie and S. Wolfe to H. Varmus, 12 December 1996; letter from P. Lurie and S. Wolfe to H. Varmus, 14 December 1996.
11. Letter from P. Lurie and S. Wolfe to H. Varmus, 17 October 1996.
12. Report to the Advisory Committee to the Director of the Panel to Review the Aspects of the Study "Interventions to Reduce HBV, HCV, and HIV in IDUs," Bethesda, MD, 12 December 1996.
13. A. L. Caplan and G. Annas, *Washington Post* (11 February 1997).
14. R. Bayer, C. Levine, S. M. Wolf, *J. Am. Med. Assoc.* 256, 1768 (1986); Office for the Protection from Research Risks, *HIV Seroprevalence Survey of Childbearing Women: Testing Neonatal Dried Blood Specimens on Filter Paper for HIV Antibody* (CDC, Atlanta, GA, 1988); *Guidelines on Ethical and Legal Conditions in Anonymous Unlinked HIV Seroprevalence Research* (Government of Canada Federal AIDS Centre, Ottawa, Ontario, May 1988); and *Unlinked Anonymous Screening for the Public Health Surveillance of HIV Infections Proposed International Guidelines* (World Health Organization Global Programme on AIDS, Geneva, Switzerland, 1989).
15. R. Bayer, *Am. J. Public Health* 83, 496 (April 1993).
16. C. SerVaas, *Saturday Evening Post* (11 January 1998).
17. J. Dwyer, "The Privacy that Can Kill," *New York Newsday*, 15 March 1995.
18. D. M. Abramson, "Passing the Test."
19. *Congressional Record*, 19 September 1995:H9059.
20. Testimony of Gary Ackerman, Hearing Before the Subcommittee on Health and Environment of the Committee on Commerce, House of Representatives, 104th Congress, 1st Session, 11 May 1995, Serial No. 104-22:8.
21. N. Hentoff, "Another Tuskegee?" *Washington Post* 20 May 1995.
22. S. A. Spector et al., *New Engl. J. Med.* 331, 1181 (1994).
23. M. Angell, *ibid.* 337, 847 (1997).