

# Were Tuskegee & Willowbrook 'Studies in Nature'?

by DAVID J. ROTHMAN

**T**he book jacket of *Bad Blood*, James Jones's recent account of the Tuskegee syphilis experiment, describes the project as one in which "science went mad" (New York: Free Press, 1981). Apparently the case is exceptional, an aberration from normal biomedical research behavior. But put the Tuskegee experiment alongside the Willowbrook experiments of the 1950s and 1960s, in which retarded and institutionalized children were injected with live hepatitis viruses, and clearly something other than "mad science" was at stake.

Both projects pose the critical questions: what should qualify as a "study in nature"—that is, one in which the researcher is a passive observer of the course of some natural process, such as a disease, which he or she is powerless to change? And, what research designs ought to be considered ethically permissible when subjects live under conditions of overwhelming social deprivation?

## What Happened at Tuskegee

The Tuskegee syphilis experiment, described with admirable detail and clarity in Jones's book, is by now a classic case. In 1932, following a survey of the incidence of syphilis in a number of Southern regions, the venereal disease division of the U.S. Public Health Service (USPHS) began what turned out to be a forty-year project in Macon County, Alabama, to follow the effects of untreated syphilis in some 400 black men.

The study continued through World War II, when a number of the men were called up for the draft and, had they not been research subjects, would have received medical attention for their infection. It continued through the 1950s, after the efficacy of

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penicillin treatment was established, and after the Nuremberg trials produced a code of ethics for biomedical research. It lasted through the 1960s, untouched by the civil rights agitation, and unaffected by the code of research ethics adopted by the USPHS itself. It ended only in 1972, when an account of the experiment in the *Washington Star* sparked a furor.

The most obvious question, which has not received sufficient attention, is: how could an experiment that seems so clearly to violate medical ethics have been started and have continued for so long? It is both too simple and condescending to the researchers to argue that the primitive state of medical research ethics in the 1930s excuses the venture. As early as 1865 Claude Bernard asserted this familiar and still valid dictum: "The principle of medical and surgical morality, therefore, consists in never performing on man an experiment which might be harmful to him to any extent, even though the result might be highly advantageous to science, i.e., to the health of others."

One assumption is that since the experiment went on in a Southern and rural county, the "madness" afflicted only a handful of scientists. However, the list of those who were familiar with, took part in, or supported the research is staggeringly long. It includes three generations of doctors serving in the venereal disease division of the USPHS, numerous officials at the Tuskegee Institute and its affiliated hospital, hundreds of doctors in the Macon County and Alabama medical societies, and numerous foundation officials at the Rosenwald Fund and the Milbank Memorial Fund. It also includes the many readers of such medical journals as the *Public Health Reports*, the *Archives of Internal Medicine*, and the *Journal of Chronic Diseases*. These readers could not have escaped the conclusion that the untreated blacks had been severely damaged. In July 1954, an article in the *Public Health Reports*, to choose one example from many, concluded that "the life expectancy of a Negro Male between the ages of 25 and 50 years, infected with syphilis and receiving

no appreciable treatment for his infection, is reduced by about 17 percent."<sup>1</sup>

A more widely held view makes race the critical feature. Although neither Jones nor Allan Brandt put the matter so baldly, they are both more concerned with the dynamics of racism than the dynamics of medical research.<sup>2</sup> In this view it was not so much that science "went mad" as that scientists reflected the racist attitudes of American society. Clearly the fact that the Tuskegee experiment involved blacks did help shape the events, but race was not the only, or perhaps even the determinative, influence at work. Case studies, like the one by Jones, can be intellectually dangerous undertakings, for unless they are informed by a wider context one cannot easily distinguish among causative considerations. (I must relate my favorite anecdote on this point. In my family of four, my son and I are right-handed, my wife and daughter are left-handed. When my daughter was three, she quite properly concluded, on the basis of her "case study" of our family, that males were right-handed, females left-handed.) A larger perspective on Tuskegee reduces the contribution of race and gives the styles and mindsets of the research scientist much greater prominence.

Some support for this judgment comes from Jones's description of the role of the white southern doctors compared to USPHS researchers. It was the public health and medical practitioners who insisted that the Tuskegee experiment include some treatment for the subjects. (The treatment may have been too limited to be effective but it was significant enough to undercut the validity of a study of "untreated" syphilis, a point to which I will return.) Apparently the clinicians, whatever the patient's race, were biased toward treatment, while the researchers were not. Moreover, a new study by John Ettling of the Progressive effort to stamp out hookworm in the South suggests that a medical outlook could, at least to a degree, counter racial prejudices. The comparison between Tuskegee and the hook-

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di- .m campaign should not be exaggerated, for whites suffered from hookworm more than blacks. Still, in Etting's view, the director of the Sanitary Commission conducting the campaign was not "stretching the truth" when declaring in 1912 that "the work done thus far in all the state has been . . . without race distinction . . . I have never visited a dispensary without seeing both races present."<sup>3</sup> By implication, then, the significant distinction to be made in the Tuskegee study is not about skin color but professional orientation to medicine or to research.

### The Willowbrook Study

In this framework, consider the hepatitis experiments at Willowbrook, an institution for the mentally retarded on Staten Island, New York. From the mid-1950s to the early 1970s, a research team led by Dr. Saul Krugman of New York University systematically infected groups of new residents with hepatitis viruses. Here too the experiments were well known. The Krugman team published many articles fully detailing the protocol. The research was even included in Henry Beecher's 1966 *New England Journal of Medicine* listing of "ethically dubious" experiments. Nevertheless, the Willowbrook project went on. Both the explanations that the researchers offered and the dynamics that perpetuated their study reveal that Willowbrook, like the Tuskegee experience, can only be understood in the context of scientific research. Indeed, the explanations and processes in the two experiments are so similar that it will not do to note that both the retarded and the blacks are "devalued" members of society, and thus turn the two cases into examples of "mere" prejudice.

The researchers' own justifications for these projects were not simply self-serving or clearly without merit. The Tuskegee study, the USPHS insisted, constituted a "natural experiment," what Claude Bernard himself had labeled "a study of nature" (which was ethically justified): Macon County, USPHS maintained, was "a ready-made laboratory." Even if the USPHS were to forego the opportunity to track the syphilis of the Macon County blacks, it seemed certain that this poverty-stricken, isolated, and medically unserved population would never receive the only therapy that existed—a complicated,

lengthy, somewhat dangerous, and not altogether effective treatment of mercury and the two arsenic compounds known as salvarsan. (Later, some USPHS officials tried to excuse the denial of this treatment by citing its ineffectiveness; but at the time the leading point was its unavailability.) The project was ethical, the researchers could claim, because they would only be watching the inevitable. Since the subjects were not going to obtain treatment anyway, there was no reason to miss the opportunity to trace the effects of their infections.

"It is our duty and our right to perform an experiment on man whenever it can save his life, cure him or gain him some personal benefit. The principle of medical and surgical morality, therefore, consists in never performing on man an experiment which might be harmful to him to any extent, even though the result might be highly advantageous to science, i.e., to the health of others. But performing experiments and operations exclusively from the point of view of the patient's own advantage does not prevent their turning out profitably to science. . . ." *Claude Bernard, An Introduction to the Study of Experimental Medicine (1865). Trans. by Henry C. Green (New York: Dover Publications, 1957).*

The Krugman team offered the same type of argument. It too was conducting a natural experiment, even while infecting the residents with live viruses, for hepatitis was endemic to Willowbrook. A new resident would in all probability contract the disease within a matter of weeks. The counterpart at Willowbrook to the poverty and lack of education of the Macon County blacks was the substandard hygienic conditions and staff shortages that made contagion so likely. If the Krugman team did not infect the newcomers, they would get hepatitis anyway. Hence, what harm or ethical violation would occur by administering the virus oneself, observing the course of the disease, and, in this instance (but not the Tuskegee one) attempting to find a cure?

Further, both the USPHS and the Krugman team insisted that their research would even provide some immediate advantages for the population under study. In Tuskegee, the "benefits" included free aspirin, "spring tonics," \$50 burial payment, and the psychological reassurance of having people come all the way from Washington to examine you on a periodic "round-up." At Willowbrook the "benefits" were being placed on the Krugman ward, which was cleaner, better supervised, and had a much higher nurse/patient ratio than the general wards. In this setting, the course of the illness would be much more closely monitored and complications would be less likely to occur. (There is a side issue of whether one of the "benefits" also included admission to Willowbrook itself since the general wards had been closed because of overcrowding. Later the Krugman team denied that such a benefit ever existed, explaining instances to the contrary as administrative errors.)

Accordingly, in both Tuskegee and Willowbrook, researchers insisted that their protocols were ethical. Given the inevitability of the black subjects not receiving treatment and the retarded residents contracting hepatitis, the researchers were only passive observers of a natural phenomenon.

There is, to be sure, a valid category of "natural experiments" within the health sciences. When no known and effective treatment exists for a disease, then to observe its course (with the informed consent of the subject) is "natural." Or, where carriers of a disease pose an unknown risk of contagion and no intervention can erase their carrier state, then to conduct epidemiological studies measuring changes in the incidence of the disease also qualifies as a natural experiment. But do Tuskegee and Willowbrook belong in the category?

No, because there is an essential difference between taking advantage of *social*, as opposed to biological, conditions. Poverty, ignorance, filth, and institutional miseries are not in any way comparable to the inevitable course of a mysterious disease or the unknown risks posed by carriers. Indeed, the Tuskegee and the Willowbrook experiments offer both practical and principled support for maintaining as rigid a distinction between social deprivation and biological conditions as possible.

On the practical side, predictions of continued social deprivation—that the Tuskegee subjects will not receive medical attention or Willowbrook residents will contract hepatitis—tend to become self-fulfilling. The researchers themselves prevented the blacks from obtaining treatment when a draft call-up or the advent of penicillin would have made it possible. Researchers may develop such an immense stake in their projects that they will intervene to maintain the necessary level of social deprivation. Time after time in the Tuskegee study its directors presented a variety of rationalizations to keep the project going long after it was apparent that whatever justifications might have existed at the beginning had since disappeared. After penicillin, the researchers argued that the study had to continue because there would never again be such an opportunity to examine the long-term effects of the untreated disease. After the study had been severely attacked on methodological grounds (since many of the subjects actually were not "untreated"), the researchers argued that the project would now also observe the aging process in the subjects. And even after the study had been attacked on ethical grounds the researchers argued that it had to continue to its scientific conclusion; otherwise all the earlier harms would have been done in vain.

The Willowbrook research reveals a similar dynamic at work. Here the project continued even after the efficacy of gamma globulin to weaken (if not to prevent) an attack of hepatitis had been established, and even after the project had been attacked by Beecher on ethical grounds. Having already distinguished hepatitis A from B, the researchers seemed on the verge of discovering a vaccine—and the mere fact that the original "deprivation" had changed could not halt the momentum.

Experiments that build upon social deprivation are likely to manipulate the consent of the subjects. In Tuskegee the blacks were informed that they had "bad blood," not syphilis, and so were kept ignorant of the potential risks of contagion. When painful procedures like lumbar punctures were done, the experimenters systematically lied. Procedures at Willowbrook were no better. The consent form that parents signed to allow their children to be infected with the virus read as though their children were to receive a

vaccine against the virus. Thus, the very deprivation that justifies the research makes it very likely that the rights of the subjects will be flagrantly disregarded.

In principled terms, social deprivation ought not to become the occasion for conducting a seemingly "natural experiment," for researchers place themselves in an ethically untenable position. As soon as they attempt to take advantage of the social predicament in which the subjects are found, they become accomplices to the problem, not observers of it. For usually the investigators have the ability to alter the social deprivation of their particular subjects, although not the larger class that they represent. The USPHS could have treated the 400 Macon County blacks, reduced their risks of contagion, and increased their longevity, albeit not that of the thousands of other untreated victims of the disease. The Krugman team could have administered a unit at Willowbrook where several hundred new residents would have enjoyed a clean and well-staffed environment and not contracted hepatitis, although their counterparts in this institution and others would not have been affected. To be sure, neither the USPHS nor Krugman had the immediate authority or funds to carry out such ameliorative efforts. But had they brought the same zeal to providing treatment as to conducting their experiments, had they pursued foundation and government grants for treatment, they might well have succeeded. Neither Macon County nor Willowbrook would have impeded their efforts. In other words, where the essential cause of a health problem is social deprivation, it is generally within the power of the research team to remedy the situation for their subjects. Hence, they cannot be "observers" to a plight they could improve.

Before their particular projects began neither the USPHS nor the Krugman team was under a special obligation to the blacks of Macon County or the Willowbrook residents, or at least an obligation different from that of the rest of society. The mandates of public health or viral research teams could reasonably be drawn so as to exclude these particular groups from their agendas. But once the research began, once the teams arrived and "observed," then their responsibilities for the suffering that they could have alleviated changed. A counter-argument that unless researchers take advantage of this social

misery they will not be able to help a larger number of other victims of syphilis or hepatitis immediately recalls Bernard's dictum not to inflict harm on one group for the advantage of another. And by the same token, justifications that the Tuskegee or Willowbrook research "benefits" the subjects through the payment of a few dollars or better monitoring of their illness become specious when compared to the possibility of the genuine benefits that could have been delivered.

Ironically, neither the Tuskegee project nor even the Krugman research was vital to the progress of medical science. It may be wishful thinking to hypothesize that bad ethics makes bad science; but surely it is reasonable to consider whether the chaotic conditions that accompany situations of social deprivation make well-designed research projects difficult to design and implement. The Tuskegee study offers ample support for both propositions. Its science was not so much mad as bad. The research began without formal protocols, continued sloppily, and never produced substantial findings. The Krugman research was more sophisticated, but here too lapses in design (especially at the start of the project) could be traced back to wretched conditions at Willowbrook. The critical breakthroughs in identifying the hepatitis B virus occurred in the laboratories of other researchers. (The Nobel Prize for the work went to Dr. Baruch Blumberg and his institute holds the patent to the new vaccine.) It may have been serendipity, but hepatitis B would have been conquered had the Krugman team never infected one Willowbrook resident.

Two cases do not establish a principle, but in these instances, neither ethics nor science gained much from "observing" conditions of social deprivation.

## REFERENCES

<sup>1</sup>J.K. Shafer, M.D., et al., "Untreated Syphilis in the Male Negro," *Public Health Reports* 69 (1954), 688-89. Although the article did not clarify the nature of the subjects' consent, readers had good reason to be suspicious of just how "informed" it was.

<sup>2</sup>Allan M. Brandt, "Racism and Research," *Hastings Center Report* 8 (1978), 21-29. Covering a great amount of material in a short space, Brandt could devote no more than limited attention to the scientific issues involved. He clearly recognized many of them, but did not address them.

<sup>3</sup>John Entling, *The Germ of Laziness* (Cambridge: Harvard University Press, 1981), pp. 173-74.