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Tuskegee syphilis study's fallout debated

Researchers split over whether blacks are more mistrustful of clinical trials

Ap Associated Press updated 11:59 a.m. ET, Sun., March. 16, 2008

MONTGOMERY, Ala. - The infamous Tuskegee Syphilis Study, a government experiment that charted the effects of the untreated disease on mostly poor and uneducated black men, was conducted for 40 years before it was exposed and ended in 1972 amid widespread condemnation.

A number of participants in the study died of the disease, which the men spread to women and to children at birth.

But does it still take a toll on the health of new generations of blacks?

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Gail Burton / AP

Dr. Thomas LaVeist, director of the Bloomberg School's Center for Health Disparities Solutions, says the Tuskegee study plays only a modest role in producing distrust.

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Even the experts, apparently, can't agree.

Two separate studies by Johns Hopkins University physicians took opposing sides on whether the Tuskegee experiment remains a significant factor in turning blacks away from clinical trials at a greater rate than whites. And both tended to contradict an extensive 2005 National Institutes of Health computer survey that found, in fact, blacks are no different than whites in the rate at which they take part in clinical trials when offered the chance.

Despite the different findings, researchers

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involved in the studies, along with others who work on minority medical issues, said more needs to be done to make sure blacks have proper access to clinical trials as well as medical care.

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In research reported earlier this year, Johns Hopkins University doctors found that blacks were more reluctant than whites to take part in medical studies because they fear being improperly used as guinea pigs. Their lack of participation, the authors said, inhibits efforts to develop treatments for diseases that blacks suffer from in disproportionately large numbers.

"So long as the legacy of Tuskegee persists, African-Americans will be left out of important findings about the latest treatments for diseases," said senior study author Dr. Neil Powe, a professor at Johns Hopkins School of Medicine.

"There is enormous irony that without African-American subject participation in clinical trials, we are not going to have tested the best therapies we need to treat African-Americans," Powe said.

But less than three years earlier, researchers from the Johns Hopkins Bloomberg School of Public Health reached a different conclusion about the Tuskegee experiment. Their study published in the July 2005 issue of the Journal of the National Medical Association found that few blacks had heard of the Tuskegee experiment and fewer knew accurate facts.

Mistrustful of medical care

They agree with Powe that blacks are significantly more likely than whites to be mistrustful of medical care and clinical trials. But they don't view the experiment conducted by the U.S. Public Health Service in Macon County, Ala., to be a major reason.

Dr. Thomas LaVeist, co-author and director of the Bloomberg School's Center for Health Disparities Solutions, said the Tuskegee study plays only a modest role in producing distrust.

Instead, LaVeist said emphasis should be placed on contemporary factors that may make blacks less likely to want to participate: They're more likely to go to lower quality health care facilities, they have more difficulty getting appointments and they experience longer waiting times. All supporting the notion that blacks aren't treated the same, he said.

"Of course, we cannot undo a historical event," he said. "(But) to place so much emphasis on Tuskegee is to divert attention away from possible causes and solutions that could possibly be effective today."

The Tuskegee Study was exposed by The Associated Press in a report in July 1972. To learn more about the disease, the federal program had enlisted 600 black men in the experiment — 399 with syphilis and 201 without it — in exchange for free medical exams, meals and burial insurance.

Those with the disease were not told they had it and were denied treatment with penicillin when it began being used in the mid-1940s. When the study was exposed, 28 men had died of syphilis, 100 others had died of medical problems related to it, at least 40 wives had been infected and 19 children contracted the disease at birth, according to federal records.

A lawsuit ended in a settlement providing at least \$9 million to those harmed, Congress called for reforms to protect human subjects in



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studies, and in 1997 President Clinton apologized to survivors for research that was "deeply, profoundly, morally wrong."

The legacy of the study has been cited by other medical officials, including those fighting the disproportionate number of blacks infected with AIDS in the past decade.

Not asked as often

But the NIH computer survey released in 2005 found that minorities are actually willing to volunteer at the same rate as whites, but aren't asked as often. The data was compiled from a range of trials and research over two decades.

"Our data suggest that when they're eligible and know about a trial, they enroll at the same rates as non-Hispanic whites do," said David Wendler, a bioethicist who helped lead the NIH research.

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Wendler said he believes the Tuskegee legacy remains a problem, but feels it's not nearly as significant a factor in people's actual decisions as more practical concerns — whether they know about the trial, or whether they can take time off work.

Wendler said the results in the NIH study may differ from Powe's because the institute researched actual trials while Powe's involved hypothetical questions.

"What they found was that in response to those hypothetical questions, African-Americans are less trusting," he said. "We know people have different attitudes toward hypothetical and real cases."

The study by Powe and other Johns Hopkins physicians, released in the journal Medicine online Jan. 14, involved a random survey of 717 outpatients at 13 cardiology and general medicine clinics in Maryland from April to October 2002. Thirty-six percent of participants were black, the rest white.


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