



Tuskegee, a Cloud Over Research

Minorities Are Not Participating Enough In Clinical Trials

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As vice president for community and external affairs at the University of Chicago Hospitals, Michelle Obama has driven real change in relations between the institution and the mostly black neighborhoods surrounding it, working to lessen the distance between the hospital system and African American patients, neighbors and local businesses.

But when university researchers proposed enrolling local girls in a clinical trial testing the HPV (human papillomavirus) vaccine, which can prevent cervical cancer, Obama stopped the project. According to the New York Times, "The prospect of white doctors performing a trial with black teenage girls summoned the specter of the Tuskegee syphilis experiment of the mid-20th century, when white doctors let hundreds of black men go untreated to study the disease."

The legacy of Tuskegee is etched on the landscape of clinical research. In 1932, U.S. Public Health Service doctors enticed 399 poor black men into a study whose aim was to observe the natural progression of untreated syphilis. At the time, most treatments for syphilis were ineffective and dangerous. But by the late 1940s penicillin had become the standard treatment for syphilis -- yet the study, inexcusably, continued until 1972. Twenty-five years later, President Clinton publicly apologized to the eight surviving participants of the shocking and unethical study, saying, "What the United States government did was shameful."

Acknowledging the fact that Tuskegee remains a touchstone of African American mistrust of the medical system is essential. Yet, as Democratic presidential candidate Barack Obama has suggested about other aspects of relations between Americans of all colors, it also deserves "a serious and thoughtful conversation."

Today, African Americans have one of the highest rates of high blood pressure in the world; they are twice as likely to have diabetes than are whites; they have the highest asthma rate of any racial or ethnic group; they have the highest mortality rate for all cancers combined; and the black population is the most likely to be afflicted with sickle-cell anemia.

There is a desperate need to develop new medicines for diseases that disproportionately affect African Americans, and there is a growing body of evidence that minority and ethnic populations respond differently to certain medications. In fact, in 2005 the Food and Drug Administration for the first time approved a drug specifically intended for use by African Americans with congestive heart failure, who responded less effectively to available medicines.

Today minority patients are underrepresented in clinical trials. African American, Latino and Asian populations account for about one-third of all Americans, but less than one-tenth of U.S. clinical trial participants come from these groups.

Why?

In large measure, it's because too few minority physicians participate in clinical research. Black and Latino physicians are more likely to treat patients of similar race and ethnicity, and there is considerable evidence that a physician's race is an important factor in influencing patient participation in a clinical trial.

The first step in addressing the underrepresentation of black Americans in research, then, is to recruit more minority physicians into clinical research. Government agencies and research companies must proactively reach out to physicians practicing in minority communities and reduce the barriers of time, money and training that make it difficult to incorporate clinical research into the general practice of medicine.

It's important, too, to reach out directly to African Americans and to demonstrate that participation in high-quality, ethical clinical research is in the best interest of their community. And here the news may be better than expected; a review of recent clinical research studies showed that younger African Americans are as willing to take part in clinical research as are non-African Americans, and the legacy of Tuskegee was not cited as a major deterrent to enrolling in a study.

Without clinical study participants of all races and ethnicities, promising new drugs cannot be fully evaluated for safety and effectiveness. It is time for the clinical research community and the public together to move beyond the inexcusable history of Tuskegee.

All our communities -- black and white, Latino and Asian -- need new treatments for cancer, heart disease, Alzheimer's, HIV, obesity and high blood pressure.

We should encourage our family, friends and neighbors to "give back" to the community by taking part in clinical trials where appropriate. And when young women of any race are willing to be part of a study for a vaccine against cervical cancer, they should be saluted as medical heroes in the fight against diseases that affect us all.

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