More African Americans need to participate in clinical trials

By David Satcher  February 21, 2014

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Every February our society measures its progress in the march toward equality as part of Black History Month. But seldom do we discuss inequality in health, an injustice that continues to plague African Americans.

A whole host of health disparities remains unaddressed, including Alzheimer’s — a disease that African Americans are two to three times more likely to develop than non-Hispanic whites. This disparity is rooted as much in our cultural heritage as in our genes.

For years, studies have found that African Americans have a profound mistrust of doctors and scientists. Consequently, we participate in clinical trials at far lower rates than other ethnic groups, which helps to perpetuate the sort of disparities seen with diseases such as Alzheimer’s. This fear of clinical trials dates to a dark chapter in our shared history: the Tuskegee syphilis experiments.

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The Tuskegee study was an infamous clinical experiment in which researchers and the U.S. Public Health Service led African American men with syphilis to believe that they
were receiving free medical care while, unbeknown to them, they were being left untreated so scientists could study the effects of prolonged syphilis. After the Associated Press exposed the truth, sparking a public outcry, the U.S. government ended the study in 1972, 40 years after it began.

The **1974 National Research Act** set new guidelines for the use of humans in clinical studies. In 1997, the Clinton administration worked with higher education institutions to usher in new training requirements and ethical standards for physicians, researchers and medical students as part of an *official apology* President Bill Clinton issued on behalf of the nation to the victims of the experiments. While these standards go a long way toward helping to prevent future such experiments, much damage was already done among African Americans.

More than 40 years later, memories of the Tuskegee study have not faded, nor should they. But we should not allow the horrors of that study to loom over us to our detriment, and increasing African American enrollment in clinical trials is critical. We can start by better equipping physicians with easy-to-access information about the location and requirements of clinical trials so doctors may more easily refer their qualified patients. Without higher levels of participation among African Americans, we will never unlock the root causes of the disparate impact of a disease such as Alzheimer’s. Every day that African Americans continue to live in fear of such trials is another day that we fall further behind in the fight against Alzheimer’s and other diseases.

Alzheimer’s has major **health implications for African Americans** but also has a huge impact on families’ financial stability. In 2012, **African Americans accounted for one-third** of the cost of care — around $71.6 billion — for Alzheimer’s, despite accounting for less than 14 percent of the population, researchers at John Hopkins University found in 2013. While Medicare and Medicaid bear most of the costs of medical bills associated with Alzheimer’s care, African Americans paid more than $3.45 billion out of pocket on care in 2012. Then there is the high toll of informal care, which is about 61 percent of the cost of
Alzheimer’s for African Americans. Sadly, this type of care can have even deeper economic repercussions as more and more African Americans drop out of the workforce or delay college to care for their loved ones.

Alzheimer’s cases in the United States are projected to triple from 5.2 million to nearly 14 million by 2050. In other words, these problems are going to get worse before they get better. Researchers believe it is possible to stop Alzheimer’s with investments in research equal to the size and scope of the disease. But funding can go only so far without a corresponding increase in patients willing to participate in innovative clinical trials. As one of the groups that has the most to gain from Alzheimer’s clinical trials, African Americans should lead by example. In doing so, we just might gain meaningful insight into the causes of the disparate impact of Alzheimer’s and help speed our pace to a cure.

We might also finally escape the shadow cast by Tuskegee that has helped to perpetuate a form of inequality in health care, something Martin Luther King Jr. called the worst of all types of inequalities. That would be a fitting way to honor those who went looking for care only to find injustice.

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