

The human guinea pigs: the tuskegee syphilis study term paper examples

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The Tuskegee Syphilis Study took place more than 70 years ago in Tuskegee, Alabama. The study was conducted by the Public Health Service (PHS) (Prograis 21). The study was originally entitled the " Tuskegee Study of Untreated Syphilis in the Negro Male" (Northridge 1271). There were 399 African American men that were diagnosed with syphilis but were never told of their diagnosis, never treated, and were watched and studied as the disease progressed so that the symptoms could be studied. Many of the men in the study died as a result of their illness. The survivors were denied penicillin after its discovery so that the study could continue, which it did until 1972. None of the men knew, nor were their families ever told, that their illness could have been treated. It was not until the 1990s that President Bill Clinton gave a formal apology about the government's action about the study. He held a much deserved ceremony to remember the participants of the study and gave a mere \$200, 000 in seed money from the federal government to establish the Tuskegee University National Center for Bioethics in Research and Healthcare. Within two years, by the time the center opened, another \$20 million in grants and pledges had been added to the initial sum (Prograis 21).

The PHS offered the 200 men incentives, or enticements, to participate in what they were told was a health research study (Prograis 23). Dozens of the men that were recruited for the study were members of the Shiloh Church (Northridge 1271). Most of the men were poor and illiterate. In exchange for their participation, the men were offered free incentives, including rides to and from the clinics, hot meals on days when they were examined, physical examinations, and care for minor ailments. In addition, for most of these

men, there was also the allure of a guaranteed burial stipend to be received by their beneficiaries upon their death. It was the only burial insurance that these men would ever hope to have, even though the modest sum of \$50 in 1932, to be adjusted for inflation, seemed like a fortune to many of them at that time. The researchers did not see these men as humans who had families who depended upon them. There was no compassion to treat a disease that ravaged and ultimately killed them as data was gathered for the sake of research (Prograis 23).

Partially because of the public outcry since 1972, when the Tuskegee Syphilis Study parameters were published, there are now prerequisites in place for clinical trials. Participants must give informed consent to participate in the study. There must be attempts made to minimize the potential risks. Participants have the right to confidentiality. Although physicians have had guidelines, such as the Hippocratic Oath, for a long time, scientists have been practicing with similar guidelines for only a few decades. In vitro studies, research on humans, and even research on animals now have to pass stringent guidelines before implementation and are closely monitored throughout the course of the study. Additionally, the international community is involved with guidelines for ethical conduct such as the Professional Ethics Report published by the American Association for the Advancement of Science (Pang 1068).

Medical ethics continues to be a matter of investigation and discussion in modern times as well. Sir David King, Chief Scientific Adviser to the UK Government, spoke about the universal ethical code for scientists and described them simply as "Rigor, respect and responsibility" (Pang 1068).

This was the quote made by King at a speech that he gave at Imperial College in London in 2007. With this code, scientists are called to be accurate and honest when presenting scientific evidence, be able to declare a conflict of interest when necessary, and take steps to prevent professional misconduct from occurring in their own work or within the profession. The most important part of King's code is that all attempts should be made to minimize any adverse events from occurring, and if they do occur, be able to justify the need for exposing people to such risks (Pang 1068).

It is more difficult today to engage African Americans, as well as other minority groups, in medical research studies. Many scientists and sociologists blame this reluctance on the Tuskegee Syphilis Study. Others state that it is a general distrust of the medical community which is dominated by white practitioners. Yet others believe it is the long history of oppression that African Americans have suffered at the hands of whites that leads to the resistance. Medical researchers do need to accept some of the responsibility for the mistrust that they do receive. There are a substantial number of diseases that affect African Americans in greater numbers than whites. It is essential to have African Americans participate in research studies to test genetic predisposition and enable the skilled clinicians a chance to try and rectify imbalances or discover a way to assist African Americans in increasing their odds in surviving these diseases

(News 33).

Studies that follow the participation of all groups in medical research has proven what people in the minority groups have known for many years.

Whether it is explicit or subtle in manner, intentional or unintentional, there

is racism in the medical profession. Five years after an initial study, a follow-up report by the National Healthcare Disparities Report in 2007 found that during the five years of supposedly active attempts to reduce disparities between races and socioeconomic groups little had changed. There are three key themes that emerged from the reports. The disparities in healthcare between whites and other groups in the population have not lessened (Clark 118). The gaps in quality and access have not been diminished. Lack of insurance is one of the biggest barriers to minorities receiving adequate healthcare. In many ways, the latter is similar to the 1932 reason that many of the participants were drawn to the Tuskegee Syphilis Study, the lure of free healthcare. It has been 80 years, and some of the same injustices are still affecting the African American society.

Interventions to correct these issues need to be implemented at the individual, community, and national levels. One of these issues is the development of partnerships that will help to develop a trusting relationship between minority communities and members of the medical community. Another issue is having insurance coverage extend to cover more people and with fewer restrictions than the current system dominated by private insurers. Lastly, situations that have occurred, such as the injustices of the Tuskegee study, need to be mentioned and brought to the enlightenment of everyone as a medical injustice. In the white community, few people have heard of this study and practically no white people were ever affected by it (Clark 119).

The blatant disregard for human life by the researchers did surprise me. Although I had heard of the study, I was not aware of how many men were

affected and that their symptoms, in some cases, had been ignored for 40 years. I selected this case because I had heard about the study in class and was surprised that our government could participate in an experiment that had such a disregard for human life. The fact that any researcher could collect data on human subjects and demonstrate compassion for what was occurring to these men is astonishing to me. I am pleased that there are set guidelines to help prevent a future similar tragedy from occurring not only in this country, but in the international community. I also did not consider the possible lingering effects of African Americans still fearing to participate in research studies, whether the fear be conscious or subconscious, it does seem like it does exist. Getting more African Americans to participate in research can only help increase the lifespans of future generations.

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