

Conflict between medical research and ethics



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Medical Research and EthicsThere is a fine line between medical research and ethics. The problem is researchers or the research itself has a tendency to go beyond the limits of medical ethics due to measures taken in the pursuit of unknown knowledge. I will be using the Tuskegee Syphilis Study for the basis of this opinionated paper. I will be disclosing my findings as well as my opinion on the Tuskegee Syphilis Study in this paper.

In this paper I will be disclosing the facts concerning the study and its significant influence on the culture of Black American culture during the time of the study. I disagree with various aspects of this study, such as how the study was handled, how the patient was uninformed along with lack of consent, and how the life and health of the patient were affected as a result of the study. The Beginning of the EndThe Tuskegee study of the 1930s, which ran 40 years, was the biggest controversy in medical history. It set the standards for the African American community in the medical world today. Therefore, the African American community is more reluctant to be involved in health screenings and public health issues.

Dr. Stephen B. Thomas and Dr. Sandra Crouse Quinn conducted a review of The Tuskegee Study of the 1930sTM and wrote an article in 1991 titled ??? Light on the Shadow of the Tuskegee Syphilis Study???. Thomas and Quinn states, ??? The strategies used to recruit and retain participants were quite similar to those being advocated for HIV/AIDs prevention programs today.

Almost 60 years after the study began, there remains a trail of dishonest and suspicion that hampers HIV education efforts in Black communities??? The Tuskegee study started in 1932 in Tuskegee Alabama. The Public Health System (PHS) became interested in the area because of the high rate of syphilis, and ??? located the men who became the study??™s unwitting subjects, (Reverby, 2001, p. 2).

??? This was an easy task because of the poverty levels and lack of health care access in the Black community during this time. The fact that Whites ruled Blacks in Macon County during the 1930??™s, coupled with the Black men??™s extreme poverty and almost lack of access to health care, made the men willing subjects. As Dr. Frost, a black physician from the Rosenwald Fund stated, ??? as a group they were susceptible to kindness (p. 1500).??? The way that the PHS did not inform the patients of their illness because they thought they were too ignorant to understand, shows a complete lack of ethics. According to Thomas and Quinn (1991), ??? participants were not informed that they suffered from a specific, definable disease that was contagious and transmitted through sexual intercourse. Nor were they told the disease could be transmitted from mother to fetus (p.

1501).??? The PHS showed a complete disregard for human life, just to gain a better understanding of the unknown factors of syphilis. They also breached medical ethics by not informing their participants of the type of disease they had, nor did they use the proper amounts of medication to help cure the disease, if any were given at all. Instead, they preyed on the vulnerable, poor, unknowing souls, which the PHS knew would not and could not afford to turn down the incentives of free food, physical examinations,

transportation, and burials for those who passed from the disease. The Treatment The ultimate tragedy of the Tuskegee experiment was exemplified by the extraordinary measures taken to ensure that subjects in the experimental group did not receive effective treatment. During World War II, approximately 50 of the syphilitic cases received letters from the local draft board ordering to take treatment. The PHS requested they excluded the men in the study and the draft board agreed.

When treatment finally began in selected clinics across the nation, the Tuskegee patients were excluded again. Director of Venereal Disease, Dr. John Heller, at the PHS during the Tuskegee study stated, "the men's status did not warrant ethical debate. They were subjects, not patients" clinical material, not sick people (p. 1501).

It is very clear that the professionals who carried out this study only saw the participants as a means to an end. They showed total disregard for the participants rights to know what was going on, took away their free will to choose whether they wanted to continue being participants or not, and had total lack of humanity and compassion. These participants were only ignorant to the disease that was killing their body because no one saw fit to give them the knowledge or the means to combat it. A holocaust scholar had suggested that "understanding threatens to cripple judgment, because to understand is almost to justify, even when it is not an author's intention (Reverby, 2001 p. 6). If I had been a manager of one of these studies, I would have ensured that the participants were treated as equals and given the best care possible at the time. I, under no circumstance would put their lives on the line to collect data.

I would let them participate as long as their blood levels were low and could withstand the trials, but once I saw the disease progressing, I would have given them full treatment. The PHS went to extremes to ensure that participants of the Tuskegee study did not receive treatment. The PHS did many things to keep the men from treatment: tracking them to other public health departments across the country, intervening with local physicians, and even the local draft board, perpetuating the falsification that they were being treated by providing aspirin and vitamins. If the participants had been given treatment, the side effects of killing the disease-causing spirochetes would have been evitable.

In an asymptomatic person, the side effect could cause fevers, dangerous cardiovascular damage, and life-threatening harm. This should have been a warning sign to the physicians and other public health professionals when one of the study participants managed to get their attention. However, in the medical field it is unlikely that one professional will debate another's when it seems all facts are in place (Reverby, 2001 p. 6).

. The AftermathThe Tuskegee study had a profound impact on the African American culture. It embarked the fear in the community that health care professionals were dishonest and medicines prescribed were not efficient.

An example stated by Reverby concerns over rising AIDs rates, the African American community's lack of participation in clinical studies, and revelations of abuse of research and informed consent protocols in the nation's leading medical schools and hospitals also added to Tuskegee's

™s ascending metaphoric status (p. 5).??? Because of this profound influence, it is even harder to prevail on the African American community to embrace the new health care forums today.

They are unwilling to participate in study??™s that will help us gain more insight into the various diseases and try new clinical treatments available for the current diseases. Dr. Donald Printz an official in the Venereal Disease Branch of the Center for Disease Control (CDC) publicly stated ??? The experiment was almost like genocide.

A literal death sentence was passed on some of those people (p. 1502).??? In actuality that is what was done. The PHS at that time willing did not give the participants treatment because in doing so would ruin the chances of finding the data they needed to solve the mysteries of syphilis. In addition, the African Americans were prime targets for this study. There were no White participants.

If this study were done using White people as participants, this would not have been the case. They would have been duly informed of all risks and factors. This leads the society as an entirety to believe this was a racial study. I strongly believe that this was an underlining racial prejudice and attempt to wipe out the ??? Negroes??? as they were called back in that time. The study of syphilis was just a cover up for the genuine reason they withheld treatment to these participants.

According to Tuskegee University (2003-2010), ??? during this period, there was a debate occurring in health circles about possible racial variations in effect of syphilis. Dr. Taliaferro Clark of the PHS suggested that the project

could be partially ??? salvaged??™ by conducting a prospective study on the effects of untreated syphilis on living subjects. In doing so, they wiped out a large number of African Americans with their very clever guise, until 1972 when the truth finally revealed itself. According to Thomas and Quinn (1991), ??? it was Peter Buxtun who stopped the Tuskegee Syphilis Study by telling his story to a reporter with the Associated Press. The Washington Star ran a front-page story about the experiment. The story was picked up off the wire service and became front-page news.

It did not take long for officials in the Department of Health, Education, and Welfare (HEW) and the PHS to form a chorus of denunciation in concert with the public outcry condemning the study. Little effort was made directly to defend or justify the experiment. In addition, this led to the congressional subcommittee hearings in 1972 by Senator Edward Kennedy. The result was a complete revamping of HEW regulations on protection of human subjects in experimentation.

In my opinion, this was a revolutionary move for the African American??™s Civil Rights movement in the 1970s. My concluding statements to this research paper are simple. The Tuskegee Syphilis Study is one of the most horrendous examples of research carried out in disregard of basic ethical principles of conduct.

The publicity surrounding the study was one of the major influences leading to the codification of protection for human subjects. The Tuskegee Study was a defamation of character for the health care world and its participants. It embarked a different meaning for a whole culture.

In other words, it set the outlook that health care is not trustworthy and relies on falsifications to obtain the means necessary to thrive. I realize that is not the way the health care industry wants to be perceived. However, it is perceived that way through the eyes of the African American??™s culture today, as a result of the Tuskegee study. Nevertheless, without this huge controversy, we may not have the laws and regulations that help protect humans in research today. In addition, there may not be the strict guidelines that protect Personal Health Information (PHI) and assistance in preventing unethical use of one??™s information to withhold treatment. In addition, there would not be patient??™s rights. I believe that there could have been a more merciful approach in this study than what was taken.

I think the participants should have had the right to know what ailment they suffered from, what course of actions could be taken, and been fully informed of the risks and procedures. Then if they still wanted to participate, it was with thorough knowledge of the possible consequences. I think the health care professionals involved in this study could have been more compassionate and treated the participants as individuals, instead of treating them as clinical material. References: Reverby, S M (Sept-Oct 2001). Cultural memory and the Tuskegee syphilis study: the Tuskegee Syphilis study is surrounded by illuminating misconceptions—myths that cannot be blithely dismissed because they actually provide some insight into the significance of the study. The Hastings Center Report.

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