



## Letter to Editor

### Scientific Progress and Ethic Stumbles: Tuskegee's Research

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#### To the Editor:

Scam in scientific and medical research is more frequent than it should be. It can be seen in cases of plagiarism and results which cannot be verified -including modified statistics-. In England one of the most stunning scandals took place, and it was considered one of the most important frauds of the 20<sup>th</sup> century. This fraud was carried out by Andrew Wakefield in England during the 90s, and it consisted in making up a nonexistent relation between the MMR vaccine (measles, mumps, and rubella) and the appearance of autism in 12 children. Some years later, when it was discovered that the data published was false, "The Lancet" magazine took back. Behind this deliberate scam, a serious conflict of interests was hidden: Wakefield had been hired (and paid) by Richard Barr, a lawyer who recruited autistic children's parents to sue the manufacturers of the vaccine. In spite of the appearance of new data that showed that fraud, this falsification provoked a media movement against vaccines. Even worse, the demand of MMR vaccine, which had been discredited without real proves, decreased in the United Kingdom below the recommended threshold to keep the immunity of the population. Wakefield lost his license to work in the United Kingdom. However, he says (now from the United States) that the study was valid, and that some parents of those children still support him. Wakefield should be sued due to his behavior as medical researcher. In this case it is shown once again that a revision to the ethical aspects of research is necessary as it will always be, at least, a slight contribution to doctors under training.

As it has happened with religion, the worst human atrocities have been justified on behalf of science. Frequently, black and third world populations have been used as "guinea pigs" for experiments, vaccine tests and clinical protocols carried out by important universities. Nevertheless, this use of "second hand" human beings has not been exclusive of the Nazis as it may be believed. The North American State has also done it with the state of Macon, Alabama, at the beginning of 1932 in a research known as "Tuskegee Syphilis Study" [1].

The group of study was formed as part of the division for venereal diseases of the public health service in the United States (SSH) in charge of Oliver Wenger. He was a fervent promoter of thorough research on syphilis and of the introduction of research programs in the black community. He worked with the hypothesis that syphilis affected Caucasian and black people in a different way. Therefore he observed the natural history of the disease in black, poor and illiterate men for 40 years. For this purpose, 400 black men with syphilis and 200 controls without the disease were chosen without having signed an informed consent [2].

The people involved in the Tuskegee's study did not know that they suffered from syphilis and that they were taking part in a research

study. They had been informed that they were under examination because they had "bad blood", as syphilis was commonly called at that time. Wanger was in favor of hiding the information from the subjects involved in the research because he feared that if the subjects knew what they were going through, they would not cooperate. This study ended up being evident because it was carried out without the proper respect to the subjects involved. Decades after, it caused huge changes in the way in which patients should be treated in clinical studies [3]. The study was carried out in the John Andrew hospital of the Tuskegee Institute, and its director was Dr. Eugene Dibble. Dr. Taliaferro Clark was in charge in 1932. Then, the responsible was Dr. Raymond H. Vonderlehr, who carried out the first physical tests and medical procedures. He was the one who decided to get consent from the subjects to carry out the lumbar punctures promoting the diagnostic tests as a "special free treatment". This was an unbelievable luxury for the poor black men of that time [4].

A nurse called Eunice Rivers, an Afro-American woman, was the only person from the staff who remained in the study during the 40 years that it lasted. Her presence was a crucial element in the study due to her personal knowledge of all the subjects, which made the long follow-up work. To encourage people to take part, they were offered free return transport to the clinic, hot meals in test and treatment days and burial insurance. On the other hand, in order to be accepted, the subjects or their families had to agree that researchers could perform an autopsy [3]. Researchers were trying to determine the syphilis progress without treatment, and through the autopsy they could assess the devastating effects of the disease in the human body in the post-mortem dissection [4]. Probably, if other Afro-American had known that to gain access to free medical care they had to accept an autopsy, a lot of them would have moved to Macon to receive those "benefits" [1,5].

In 1943, Dr. John R. Heller, who had been Dr. Vonderlehr's assistant, replaced him as Director of the Venereal Diseases Department in the SSH. Heller's arrival coincided with the introduction of penicillin in other SSP clinics as a routine treatment for syphilis, as well as with the formulation of the Nuremberg Code, which was aimed at protecting the research subjects' rights. But instead of treating the subjects who suffered from syphilis with penicillin and calling off the study, Tuskegee's scientists did not use penicillin or give information about it in order to go on with the study about how this disease progressed and killed the patient [5].

In 1957, the research was transferred to the Center for Disease Control & Prevention (CDC) and it carried on without important changes despite a report showing that complications were much more common in infected people and that the death rate in men with syphilis turned to be twice higher than in controls [6].

In 1966, Peter Buxtun, a researcher of the SSP in San Francisco, sent a letter to the Director of the Venereal Diseases Department telling him his concerns on the morality of the experiment. The CDC reasserted the need of carrying on with the study until it was finished, that is to say, until the subjects died and the corresponding autopsies could be performed. The CDC said that the experiment "served for the people who served" [7].

The study continued until 1972, when a leak in the media (more than any other ethical or moral consideration) made the experiment stop. The story first came out in the Washington Star on July 25<sup>th</sup>, 1972. And the next day it came out in the first page of the New York

Times. By the end of the study, only 74 subjects were still alive. Twenty-eight men had died of syphilis, 100 died of complications related to it, 40 of their wives were infected and 19 children were born with congenital syphilis.

As recognition of the undertaken responsibility, the North American government promised to give medical care and free funeral to all the people who had survived. The government is still giving economical compensation to the families of the people who had died, as it was agreed [8].

In 1996 the USA government formally apologized for the experiment. President Bill Clinton, in presence of the survivors, stated: "The American people are sorry - for the loss, for the years of hurt. You did nothing wrong, but you were grievously wronged. I apologize and I am sorry that this apology has been so long in coming. To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry" [1,8].

The survivors were old, three of them were on wheelchairs, and five travelled to Washington on behalf of all the victims and also of other three partners who were still alive but could not go to the ceremony with the president due to health problems. The doctors had had the opportunity of treating the patients in the study and they did not do it, so the words of the President would give the lawbreakers the feeling that they had behaved in the wrong way. However, the apology did not remove the horror of that event. Of course, Clinton's apologies did not excuse the Tuskegee experiment, even though those apologies may have helped to end up a terrible episode of the history of this country [7].

The Declaration of Human Rights took place more than 200 years ago. However, rights are still being cruelly violated. When the founders of the United States wrote the great words of the Constitution and the Independence Declaration, they signed a promissory note that every North American would heir. This document was the promise that each man would be granted the rights to life and freedom. It is clear that the United States has not fulfilled that promissory note as regards the black citizens. Instead of respecting that duty, the United States has given the black men a bounced check, a check that has been returned with a seal that says "insufficient funds" because as they followed the classic Darwin model of selecting the most vulnerable, hundreds of vulnerable and weak human beings have been treated inhumanly and most of them have died [8].

Frequently, the Tuskegee study and the Oslo study carried out in 1928 are wrongly compared. The Oslo study showed the untreated syphilis pathologic appearance in hundreds of Caucasian men. This study was retrospective: the researchers gathered information of patients who had already contracted syphilis and who had been without treatment for some time [9].

The Tuskegee study was prospective and it allegedly may have had the intention of measuring the prevalence and evolution of syphilis in the black race. Probably, at the beginning it was not inherently wrong if we take into account three aspects: 1- it was known that syphilis was predominant in poor black communities, 2- syphilis treatments were relatively not very effective and they had severe side effects, and 3-

researchers could do nothing as regards the therapy. Therefore, researchers could analyze the natural evolution of the disease, on condition that they do not provoke any damage to the patients. This would be in benefit of humanity.

On the other hand, the medical ethics that prevailed at that time did not have specific standards to carry out an informed consent and doctors usually hide information from patients as regards their health condition. Anyway, researchers left the reasonable good sense when the study ended up being the longest non-therapeutic experiment carried out in human beings in medical history. However, the first intention of this study, which was to "benefit the public health of the poor population" as some people suggest, started to quickly decline in three points. In the first place, to be sure that the men would accept the fact that doctors repeatedly carried out diagnostic procedures which may be dangerous [non-therapeutic] such as lumbar puncture, those men were sent tricky letters with the title: "Last chance to receive free special treatment" [10].

The second critical point in the handling of the experiment started in 1947 when the penicillin had become a standard treatment for syphilis. Several programs of the SSP in the United States started with the aim of eradicating the disease, but the subjects of Tuskegee did not receive the treatment on purpose. As there was an effective method to treat syphilis (the penicillin), the changing ethical standards, as well as the ethical and moral sense of the experiment turned to be absolutely impossible to defend [8]. The third point is that the experiment did not have any therapeutic value. In addition, it was directed by white doctors and governmental authorities who could be easily assigned racist reasons. Nevertheless, the study was carried out in the Tuskegee School Hospital, a university for black people. Moreover, black doctors and nurses took part in it, and they justified their participation saying that they would receive "additional prestige that the institution would grant" [5]. In this case, it was considered more important the potential knowledge than the basic rights of the subjects involved in the experiment [9].

The Tuskegee study is frequently mentioned as one of the most important breaches of ethic and trust between doctors and their patients. When a clinical study is carried out in the United States: is it valid on behalf of science to violate the human rights of a part of the population? Can a scientific interest prevail over the people's interests? The scientific value of any experiment could not compensate any violation of the most basic human rights, starting by the right to life. Tuskegee was the longest and most despicable study, but it was not the worst experiment in Afro-Americans [10].

The misuse of scientific research lets us analyze some of the worst sides of the human being [11]. In the case of the horrors in medical experiments on human beings, the impact is particularly strong because those crimes are committed by a member of the society who we traditionally would not expect such atrocities: a doctor [12].

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