

# Journal of Coastal Life Medicine

journal homepage: [www.jclmm.com](http://www.jclmm.com)



Document heading doi: 10.12980/JCLM.2.201414B67

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## Scientific progress and ethic stumbles: Tuskegee's research

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### To the editor

As it has happened with religion, on behalf of the science the worst human atrocities have been justified. Frequently, the black race and the third world populations have been used as “guinea pigs” for experiments, vaccine tests and clinical protocols of important universities. Nevertheless, and unluckily, this use of “second hand” human beings has not been exclusive of the Nazis as it may be relieved, but 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”<sup>[1]</sup>.

The group of study was formed as a 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 the thorough research of syphilis and of the introduction of research programmes in the black community. He worked with the hypothesis that the syphilis affected Caucasian and black people in a different way, through the observation during 40 years of the natural history of the disease in black, poor and illiterate men. For this purpose, 400 black men with syphilis and 200 controls without the disease were chosen without an informed consent<sup>[2]</sup>.

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 control because they had “bad blood”, as it was the syphilis commonly called. Wanger was in favor of hiding

the information to the subjects involved in the research because he feared that if the people knew, they would not cooperate. This study ended up being evident because it was carried out without the proper respect to the subjects and, decades after that, it led to huge changes on the way in which patients should be treated in clinical studies<sup>[3]</sup>. The study was carried out in the “John Andrew” hospital of the Tuskegee Institute, and its director was Dr. Eugene Dibble. The realization was in charge of Dr. Taliaferro Clark during the year 1932. Then, the responsible was Dr. Raymond H. Vonderlehr, who carried out the first physical tests and medical procedures, for example, it was him who decided to get a “consent” from the subjects to carry out the lumbar punctures promoting the diagnostic tests as a “special free treatment”, an unbelievable luxury for the poor black men of that time<sup>[4]</sup>.

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 because of her personal knowledge of all the subjects, which allowed the long follow-up to work. To encourage people to take part, they offered free return transport to the clinic, hot meals in test and “treatment” days and burial insurance, but to be accepted the subjects or their families had to agree that they could undergo an autopsy<sup>[3]</sup>. The researchers were trying to determine the syphilis progress without treatment and through the autopsy they assessed the devastating

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#### Article history:

Received 28 Mar 2014

Received in revised form 6 Apr, 2nd revised form 13 Apr, 3rd revised form 18 Apr 2014

Accepted 15 May 2014

Available online undetermined

effects of the disease in the human body, in the post-mortem dissection<sup>[4]</sup>. 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 the city of Macon to receive those “benefits”<sup>[1,5]</sup>.

In 1943, Dr. John R. Heller, who had been Dr Vonderlehr’s assistant, replaced him as Director of the Venereal Diseases Department of the SSH. Heller’s arrival coincided with the introduction of the 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 rejected to use penicillin or to give information about it, in order to go on the study about how this disease progresses and kills the patient<sup>[5]</sup>.

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

In 1966, Peter Buxtun, a researcher of the SSP in San Francisco, sent a letter to the Director of the Venereal Diseases Department to tell him his concerns about the morality of the experiment. The CDC reasserted the need of carrying on the study until it was finished, until the subjects died and the corresponding autopsies could be performed. The CDC excused themselves by saying that the experiment “it served for the people who served”<sup>[7]</sup>.

The study continued until 1972, when a leak in the media (more than any other ethic or moral consideration) made the experiment stop. The story first came out in the Washington Star on 25th July, 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 of the men had directly 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, and the government is still giving economical compensation to the families of the people who had died, as it was agreed<sup>[8]</sup>.

It was necessary to wait until 1996 for the USA government to formally apologize 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”<sup>[1,8]</sup>.

They were old, three of them were on wheelchairs, and five survivors travelled to Washington on behalf of all the victims and also of the other three partners of the horror who were still alive but could not go due to health problems to the ceremony with the president. The doctors had the opportunity of treating the patients in the study and they did not do it, the words of the President will give the lawbreakers a feeling of having behaved in the wrong way, because the time that passed between the event and the apology does not remove the horror of that event. Of course, Clinton’s apologies do not excuse the Tuskegee experiment, even though they may help to end up a terrible episode of the history of this country<sup>[7]</sup>.

The Declaration of Human Rights occurred 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 such 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<sup>[8]</sup>.

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<sup>[9]</sup>.

The Tuskegee study was prospective and it allegedly may have had the intention to measure the prevalence and evolution of syphilis in the black race. Probably, at

the beginning it was not inherently wrong, if we take into account that it was known that the syphilis was predominant in poor black communities, that the syphilis treatments were relatively not very effective and they had severe side effects, and that the researchers could do nothing as regards the therapy, and therefore they could analyze the natural evolution of the disease, on condition that they do not provoke a 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 the doctors usually hide information to the patients as regards their health condition. Anyway, the researchers left the reasonable good sense when the study ended up being the longest non-therapeutic experiment carried out in human beings in the medical history. However, the first intentions of this study which were to “benefit the public health of the poor population” as some people suggest to quickly decline in three points. In first place, to be sure that the men would accept repeatedly being carried out diagnostic procedures that may be dangerous (non-therapeutic) such as the lumbar puncture, doctors sent tricky letters to the patients with the title: “Last chance to receive free special treatment”<sup>[10]</sup>.

The second critical point in the handling of the experiment arrived in 1947 when the penicillin had become a standard treatment for syphilis. Several programs of the SSP of the United States were started with the aim of eradicating the disease, but the subjects of the Tuskegee were intentionally denied the treatment. As there was an effective method to treat syphilis (the penicillin), the changing ethic standards, as well as the ethic and moral sense of the experiment turned to be absolutely impossible to defend<sup>[8]</sup>.

The third point is that the experiment did not have any therapeutic value, also that it was directed by white doctors and governmental authorities who could be easily assigned racist reasons, but 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”<sup>[5]</sup>. In this case, it was considered more important the secondary potential knowledge than the basic rights of the subjects involved in the experiment<sup>[9]</sup>.

The Tuskegee study is frequently mentioned as one of the most important breaches of ethic and trust between the doctors and their patients. When a clinical study is carried

out in the United States: is it valid on behalf of the science to violate the human rights of a part of the population? Can a scientific interest prevail over the people’s interest? The scientific value of any experiment could compensate the violation of the most basic human rights, starting by the life right. Tuskegee was the longest and most despicable study, but it was not the worst experiment in Afro-Americans<sup>[10]</sup>.

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

### Conflict of interest statement

I declare that I have no conflict of interest.

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