



Tragedies in Human Medical Experimentation

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Between 1932 and 1972, a series of highly unethical medical studies were performed on a group of 400 African-Americans by doctors from the U.S. Public Health Service.

Officially referred to as the *Tuskegee Study of Untreated Syphilis in the Negro Male*, the research protocol enrolled 399 impoverished sharecroppers from Macon County, Alabama, all of whom had syphilis, and a control group of 201 others who were free of the disease. The 399 were never told that they had syphilis or that their condition was sexually-transmitted, but only that they had "bad blood."

The study began at a time when no effective treatments for syphilis existed, but as penicillin became the standard of care during the mid-1940s, the infected men were not offered the new drug; in fact, it was withheld from them during the next 25 years, to enable researchers to track the progression of their disease.

The outcry that followed the public revelation of these unethical research methods, described in an investigative report in the *Washington Star*, resulted in the study's finally being shut down. By then, there had already been widespread devastation, with 28 participants having died from syphilis, 100

more having perished from related complications, and the subjects' having transmitted the disease to at least 40 spouses and 19 of their children.

In May, 1997 President Clinton issued a public apology to the victims and their families, stating, "The United States government did something that was wrong—deeply, profoundly, morally wrong." Many afterward questioned how such ethically offensive research could have continued unabated for so many decades.

In the final analysis, the Tuskegee syphilis experiments relied upon a defective theory of ethics, still popular today, known as "utilitarianism." Utilitarianism seeks to determine right from wrong by focusing on a calculation of consequences (and so is sometimes also called "consequentialism"), asserting that the best ethical choice is the one that produces "the greatest good for the greatest number" and maximizes "usefulness."

For the Tuskegee experiments, the usefulness was the knowledge gained through studying the progression of syphilis in human patients, including what consequences (like blindness, insanity) typically can

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be expected to occur, at what stages, etc. This basic medical knowledge could end up serving the interests of thousands or millions of other individuals in the future, it was asserted, even as doctors overlooked the litany of sufferings and harms inflicted on an unfortunate few.

A utilitarian approach to justifying scientific research on humans usually implies that we need to “balance” the value of new scientific discoveries against the dignity of human experimental subjects. In this view, the two represent “competing values,” and in a world with no moral absolutes, some individuals may emphasize one set of values, while others will give more weight to another. Compromise can then open up a “middle” solution, allowing for some experimentation on humans to be carried out for the good of research, even if it might at times be harmful, debilitating or lethal to its subjects. In any real world setting, this means that those who are most vulnerable — the poor, the weak, the disenfranchised and the sick — become rife for exploitation whenever particular research goals are declared worthy of pursuit.

This utilitarian approach to “balancing values” provides a highly

flawed ethical framework that has been used to justify other immoral biomedical research projects like the German medical experiments on prisoners during the Second World War, human embryonic stem cell research, and other forms of exploitative human experimentation.

In each of these, researchers have been motivated by good goals like learning about disease, developing treatments, and helping others. Finding treatments and making progress against disease is clearly very praiseworthy. But a good end cannot justify an immoral means. That is where the need for a non-utilitarian ethical understanding becomes paramount. Maintaining immovable negative ethical norms against the abuse of research subjects is key, including norms like: “Do no harm,” “do not kill,” “always secure informed consent,” etc.

The rights of patients to these protections should not be taken as values to be balanced against the goals of research. This risks sweeping away the vital interests of human subjects in a tide of appeals to societal utility or medical progress. The negative norm, which requires that one should never harm, exploit or destroy human life in the pursuit of

laudable research goals, can only be fulfilled in one way: by refusing to violate the norm.

These kinds of negative norms serve the essential role of setting fixed and clear boundaries for ethically acceptable research, strict limits on the pursuit of even the most worthwhile of scientific goals. This helps assure that humans, who are endowed with an absolute value and a unique dignity in themselves, are appropriately protected from any forms of utilitarian reckoning.

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