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Abstract

The Tuskegee Syphilis Study was a forty year-long study in which researchers observed the natural progression of syphilis in 399 African-American men. Despite medical advancements and the discovery of successful penicillin treatments for syphilis, researchers involved in the Tuskegee Syphilis Study took extreme measures to ensure participants remained unaware of life-saving intervention (Jones, 1993). The deceptive and manipulative nature of the Tuskegee Syphilis Study resulted in public uproar and legislative action to ensure the protection of human rights and prevented future unethical practices in research involving human subjects. Although there are strict federal regulations for research ethics, underrepresentation of minority groups in clinical research continues to exist even forty years after the cessation of the Tuskegee Syphilis Study. Research suggests that the maltreatment and unethical practices of the Tuskegee Syphilis Study may have fostered distrust in health care providers resulting in unwillingness to participate in clinical research (Shavers, Lynch, & Burmeister 2000). The implications of the Tuskegee Syphilis have helped shape the American Psychological Association's Ethical Code of Conduct (2002) and influenced the current standard of care expected of health care providers involved in research.

Keywords: Tuskegee Syphilis Study, research ethics

Research Ethics: The Tuskegee Syphilis Study

The Tuskegee Syphilis Study is one of the most infamous and controversial studies executed in the last century. In 1932, the United States Public Health Service in conjunction with the Tuskegee Institute initiated a 40 year-long study to observe racial differences in the development of syphilis. Syphilis is a sexually transmitted disease that gradually spreads throughout the body and may cause physical deformities, dementia, paralysis, and even death (Center for Disease Control [CDC], 2012). Researchers from the Tuskegee Institute recruited 600 African-American men from Macon County, Alabama, 399 of whom had untreated syphilis in the latency stage (Reverby, 2001). The researchers coerced participants into the study by telling them they had "bad blood", a term used to describe multiple illnesses within the black community at that time. To persuade participants even further, researchers provided them with regular meals, free transportation to and from the clinic, and funeral stipends for their families (Carmack, Bates, & Harter, 2008). Furthermore, research directors hired African-American doctors and nurses in order to acquire and maintain the participants' trust throughout the study (Corbie-Smith, 1999).

Despite medical advancements and the 1943 discovery of penicillin as a successful treatment for syphilis, participants in the Tuskegee Syphilis Study were not privy to life-saving interventions. Furthermore, researchers prevented participants from knowing about viable treatment options by prohibiting medical screenings during the World War II draft, monitoring participants who went to other medical facilities, and intervening with other health care providers who tried to treat participants (Reverby, 2001; Rothman, 1982). By taking such extreme measures throughout the study, more than 100 men who suffered from syphilis succumbed to the curable disease (Corbie-Smith, 1999).

Although several government agencies and healthcare providers knew of the Tuskegee Syphilis Study, in 1972, the *New York Times* released an extensive article detailing the unethical treatment of African American men with untreated syphilis. The article generated public disgust and caused nationwide uproar, inevitably resulting in the 1973 termination of the Tuskegee Institute's syphilis research by the Health and Scientific Affairs Review Board (Carmack, Bates, & Harter, 2008). The unethical practices committed by researchers at the Tuskegee Institute led to the 1974 National Research Act, which mandated the use of Institutional Review Boards for research that receives federal grants (Rencher & Wolf, 2013). Despite the cessation of the study in 1973, it was not until May 16, 1997 that President Clinton issued an apology on behalf of the United States Government to the victims of the Tuskegee Syphilis Study. At this time, the United States Government recognized their role in the continuation of the study and the ethical negligence that took place (Fairchild & Bayer, 1999).

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Throughout the duration of the Tuskegee Syphilis Study, generations of researchers who undertook the study continued to rationalize their work based on scientific grounds and the importance of understanding the biological progression of the disease. They justified any ethical concerns by suggesting that researchers could never replicate the magnitude of such data or have the ability to acquire such a large group of untreated individuals (Rothman, 1982). The validations given by researchers to continue mistreating patients stress the importance of creating ethical boundaries when conducting research.

Acknowledging the deficient treatment and research decisions made by health care providers in the past helps influence the direction of patient care for the future. The Tuskegee Syphilis Study, along with many other unethical research practices in our country's medical and psychological history, including eugenics and maltreatment of the mentally ill in asylums, have helped shape the ethical requirements that are now expected from all health care providers. The ethical violations committed throughout the course of the Tuskegee Syphilis Study have influenced the inclusion of many standards outlined in the APA Code of Ethics involving patient care, therapeutic practice, and research protocols.

Ethical Concerns

General Principles

The unethical foundation and practices carried out throughout the duration of the Tuskegee Syphilis Study violated the General Principles outlined in the 2002 American Psychological Association Ethical Code of Conduct including: Beneficence and Nonmaleficence, Fidelity and Responsibility, Integrity, Justice, and Respect for Human Rights and Dignity. In terms of Beneficence and Nonmaleficence, which describes the importance of avoiding and minimizing patient harm (APA, 2002), the researchers involved with the continuation of the Tuskegee Syphilis Study harmed their participants as well as the participants' families who had to care for them as their health deteriorated due to the progression of the disease. Furthermore, researchers neglected to discuss the transmission of syphilis and preemptive measures that would prevent others from contracting the disease, which caused harm to those who had sexual relationships and children with untreated participants (Corbie-Smith, 1999; Jones, 1993).

The principle of Fidelity and Responsibility focuses on building and maintaining a trusting relationship between the patient and health care provider as well as the obligation to serve in accordance to the patient's best interest (APA, 2002). The Tuskegee Syphilis Study violated this principle and in many ways relied on deception to give the impression of trusting relationships between researchers and participants. For instance, in order to gain the trust of the participants, researchers hired an African-American nurse named Eunice Rivers for the duration of the forty year-long study. She would often transport them to and from the clinic, act as a cultural liaison, and provide devoted support to the participants (Corbie-Smith, 1999). Although this encouragement and assistance was important for the participants throughout the study, the formation and maintenance of such a trusting relationship may have inhibited the participants from making well-informed decisions about their continued involvement in the study. In this regard, Eunice Rivers may have unintentionally acted as a mode of deception rather than of trust by not upholding the participants' best interest and inadvertently obstructing informed consent.

The Integrity and Justice Principles involve the importance of upholding honesty, avoiding misrepresentation, and ensuring access and benefit from services (APA, 2002). In regards to the Tuskegee Syphilis Study, the violations of these values are apparent due to the dishonest, manipulative, and immoral nature of the study. Researchers went to great lengths in order to prevent participants from learning about life-saving treatments for syphilis including informing the Alabama Health Department not to treat participants, interceding with other health care providers, and prohibiting medical screenings for participants drafted to fight in World War II (Reverby, 2001). The resources that researchers used to maintain the study's objective indicates the unethical practices that occurred throughout the duration of the study in the name of science.

Lastly, the principle of Respect for Human Rights and Dignity concerns the protection of human rights and overall welfare of a patient's well-being (APA, 2002). Throughout the course of the Tuskegee Syphilis Study, researchers violated several human rights and exploited the vulnerability of a community affected by a potentially fatal disease. Researchers took advantage of a population that lacked affluence and quality education for African-Americans by giving participants incentives such as funeral stipends and hot meals, which inevitably impeded their ability to make informed decisions about participating in the study (Carmack, Bates, & Harter, 2008; Corbie-Smith, 1999). Furthermore, during the period in which the Tuskegee Syphilis Study took place, social prejudices against African-Americans may have influenced the basis and continued justification of the study (Bhopal, 1997).

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Informed Consent

The standards outlined in the American Psychological Association are expectations pertinent to all health care providers who are assessing, treating, or researching patients. The standard related to informed consent regarding research discusses the importance of disclosing the purpose, potential risks, and expected duration of the study in order for participants to make educated decisions about their participation in research (APA, 2002). From a historical perspective, at the time of the Tuskegee Syphilis Study the APA Code of Conduct was not a comprehensive list of standards, research guidelines, and protocols. However, the importance of informed consent is paramount in Tuskegee Syphilis Study and influences the expectations for patient care that are applicable today.

The African-American subjects involved in the Tuskegee Syphilis Study were primarily impoverished and uneducated sharecroppers, which presents ethical concerns regarding the ability for participants to make informed decisions due to desirable research incentives or an inability to comprehend the extent of their involvement in the study. Researchers also used the term "bad blood" to recruit participants rather than informing them of their actual medical condition. The lack of information provided to the participants regarding the nature of the study and treatment options indicates the inadequacy of informed consent that caused harm to many individuals involved in the Tuskegee Syphilis Study.

In addition, there remains to be controversy regarding how informed the participants were throughout the study. In 1972, a Center of Disease Control officer reported that participants in the Tuskegee Syphilis Study had knowledge of the study's nature and knew they could withdraw at any time. Conversely, Dr. Williams, an intern who worked at the Tuskegee Institute during the study, stated neither interns nor participants knew of the study's objectives (Jones, 1993). The conflicting accounts indicate the deceptive characteristics of the study, which may have caused confusion to the participants and subsequent mistrust of health care providers that is still prevalent today.

Deception in Research

The APA Ethical Code of Conduct prohibits researchers from deceiving participants in research that may potentially "cause physical harm or severe emotional distress" (p. 11). The detrimental effects caused by the Tuskegee Institute violated this standard in several ways. For instance, researchers told participants they had "bad blood" and offered treatment and incentives for ongoing participation. Medical staff involved in the study never told participants their true medical diagnosis. Charles Pollard, a Tuskegee subject stated, "All I knew was that they just kept saying I had bad blood- they never mentioned syphilis to me, not even once" (Jones, 1993, p. 278).

The participants used in the Tuskegee Syphilis Study all had syphilis in the latency stage, which can be very dangerous if left untreated. Many with latent stage syphilis may not experience the external symptoms of syphilis including sores and rashes; however, they may be susceptible to develop paralysis, blindness, dementia, or fatal damage to internal organs (CDC, 2012). Despite the debilitating and life-threatening effects of syphilis, participants never received counseling on how to prevent the transmission of disease or that their disease was contagious at all. Consequently, this exacerbated the spread syphilis and contributed to 40 wives contracting syphilis from sexual interactions and 19 children born with congenital syphilis (Jones, 1993; Perkiss, 2013).

Although the Tuskegee participants believed they were receiving treatment for "bad blood", researchers actually prevented participants from gaining access to life-saving treatment and watched as participants health slowly deteriorated. Researchers continued to justify this active neglect in fear of losing "valuable" research data due to the longevity of the study. The harm caused by the omission of information in the Tuskegee Study, especially the severity and cause of syphilis is irrevocable and continues to have ethical implications in research studies.

Research Implications

The unethical practices of researchers and health care providers throughout the Tuskegee Syphilis Study have led to legislative, political, and social implications that continue to affect research protocols. Due to the public upset caused by the revelation of the Tuskegee Syphilis Study, legislators passed the National Research Act in 1974 in hopes of avoiding unethical practices in future research endeavors (Rencher & Wolf, 2013).

The National Research Act led to the formation of the [National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research](#) who were responsible for recognizing and enforcing the ethical standards regarding professional conduct when using human subjects in research. By doing so, the Commission also established guidelines for researchers to abide by in order to protect human rights and preserve human dignity (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). The National Research Act also mandated institutions who receive government grants to establish and submit research proposals to local Institutional Review Boards. The Institutional Review Boards are required to evaluate research studies and ensure that informed consent, research methods, and objectives adhere to the ethical guidelines and uphold human rights. Moreover, the Institutional Review Boards are responsible for yearly evaluations to ensure researchers remain in accordance to all ethical guidelines. (Rencher & Wolf, 2013; Corbie-Smith, 1999).

Due to the legal and ethical implications of the Tuskegee Syphilis Study, many research institutions became overly cautious about including certain groups in their research in fear of causing another public protest. Excluding particular groups from research limited generalizability and the application of research findings to a diverse population, which consequently hindered

scientific progression. This concern led to the 1993 National Institutes of Health Revitalization Act, which required researchers to include minorities and women as research subjects. However, the ability to acquire these populations for clinical research, especially ethnic minorities, continues to be troublesome (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999).

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Although federal regulations have mandated ethical guidelines for research, the effects of the Tuskegee Syphilis Study and other unprincipled practices throughout history may be a factor in the underrepresentation of minorities participating in research and the perpetual mistrust in health care providers (Freimuth et al., 2001). Based on a report from the Center of Disease Control, African-Americans have higher rates of medical conditions including heart disease, stroke, HIV/AIDS, diabetes, and hypertension (CDC, 2011). However, due to the low census of participants in medical research, health care providers face challenges when trying to identify the physiological, cultural, and sociological reasons contributing to the high prevalence of African-Americans suffering from medical conditions.

Researchers suggest that the extensive history of unethical treatment by health care professionals, including that of the Tuskegee Syphilis Study may affect the low frequency of minorities willing to participate in research (Freimuth et al., 2001). For instance, a study conducted by Shavers, Lynch, & Burmeister (2000) indicates that knowledge of the Tuskegee Syphilis Study would negatively affect African-American participation in biomedical research based on distrust of researchers. Although awareness of the Tuskegee Syphilis Study was not the only factor influencing minority participation, 51% of African-Americans were less trusting of medical research because of their knowledge of the Tuskegee Syphilis Study. Furthermore, of the 51% who distrusted researchers, 46% reported that knowledge of the Tuskegee Study would affect their participation in medical research and 49% reported being unwilling to participant in research studies.

Misconceptions regarding the nature of the Tuskegee Syphilis Study which suggests that researchers intentionally injected participants with syphilis in order to observe the natural progression of the disease may also be a contributing factor as to why minorities are hesitant to trust researchers or health care providers (Freimuth et al., 2001; Shavers, Lynch, & Burmeister 2000). Furthermore, parental influence and socialization may have also had an indirect influence on more recent generations who were unaware of the discreditable history of research methods for scientific advancement (Poythress, Epstein, Stiles, & Edens, 2011). The influence of cultural perspectives regarding research may reinforce reluctance to participate in research and perpetuate mistrust in health care providers.

Conclusion

The ethical research concerns surrounding the Tuskegee Syphilis Study continues to influence the revisions of the APA code of conduct, the standard of care expected for all patients, legislative orders to protect human rights, and social perspectives of health care providers. Despite the cessation of the Tuskegee Syphilis Study in 1973 and the enforcement of strict federal regulations, the underrepresentation of minorities in research continues to be a concern. The lack of participation limits generalizability and impedes the validity and application of research findings. In order to facilitate change, it is important for researchers and health care providers to address the misconceptions of the Tuskegee Syphilis Study, recognize the development of ethical standards throughout recent decades, and emphasize the value of accurate representation of minorities in research.

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