



Ethical, Cultural, and Historical Leadership Implications of Conducting Public Health Research on Minority Populations


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ABSTRACT

The study focuses on ethical and cultural research into the public health sector. The content analysis of research identifies disproportionate knowledge of implications affecting the misappropriated, disenfranchised, and institutionalized minority segments of the general population affected by COVID-19 cases. Historic mistreatment of minority individuals, inmates, and the military has left a lasting negative impression of clinical research on minority groups. In 1932, the United States Public Health Service (USPHS) began a public health research study on the lethality of syphilis using African American men from Macon County, Alabama as research subjects. Referred to as the Tuskegee Syphilis Studies (or Tuskegee Experiments), researchers monitored 600 subjects, 399 of which were previously infected with the syphilis bacteria. This article looks at the historical contexts of the lack of bioethics during Tuskegee Experiments and how it currently influences African-Americans reluctance early on to get the COVID-19 vaccines and reluctance to participate in clinical trials research.

KEYWORDS

African-Americans in clinical trials, bioethics, COVID-19 Vaccine, ethical leadership, informed consent, medical ethics, public health research, research ethics

INTRODUCTION

Because of a long-standing mistrust in the American healthcare system, some African-Americans in the United States are more reluctant to sign up for COVID-19 immunizations (Elliott, 2021). This distrust is well rooted in history, notably the infamous research project on syphilis conducted in the United States, which violated the rights of some African-American males to suffer from the disease

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for the purpose of medical research (Elliott, 2021). African-Americans familiar with the syphilis study have begun discussing the vaccine's deployment (Elliott, 2021). The coronavirus epidemic and its disproportionate impact on people of color have brought to light the deficiencies in the healthcare delivery system in the United States (Elliott, 2021). For example, no hospital in Tuskegee serves the general public, and it was difficult to obtain coronavirus testing in the early stages of the outbreak (Elliott, 2021). African-Americans' unwillingness to participate in clinical trials is another factor that has residual effects (Durant et al., 2014; Swanson & Ward, 1995).

Smedley, Stith, and Nelson (2003) cite research that implies the lower number of minority participants in trials is caused by bias on the part of physicians, incorrect impressions, and prejudices around medical decision-making. According to research by Smedley, Stith, and Nelson (2003), medical professionals are less inclined to prescribe particular treatments to their minority patients. According to Smedley, Stith, and Nelson (2003), doctors make decisions based on a cognitive heuristic taught them during their medical school and residency. This heuristic causes them to carry prior expectations to each contact they have with their patients.

Research incorporating concepts of race and ethnicity can advance not only public health but also clinical care, health care, and medical science (Bhopal, 2008; Quinn, 2021). Nevertheless, researchers and practitioners need to be aware of the broader events of health improvement that are needed, particularly among African Americans (Bhopal, 2008; Wedge, 2020; Ndugga et al., 2022). Due to the distrust within the medical system, healthcare practitioners must be aware of the risks associated with providing healthcare to minority groups in public health (Bhopal, 2008; Quinn, 2021). Intentionally focusing on "doing good" should be the goal, regardless of the individual's racial or cultural background (Bhopal, 2008). Showing kindness toward members of underrepresented ethnic groups is inconsistent throughout time or across demographics (Bhopal, 2008; Quinn, 2021). According to Bhopal (2008), doing good means that enhancing the health and care of ethnic groups should be an absolute necessity and not require any particular attention or a feeling of justice (Bhopal, 2008). During the original COVID-19 epidemic, people of color and people experiencing homelessness were disproportionately affected in some communities that were underrepresented in the population (Wedge, 2020). The study conducted at the Boston Medical Center (BMC) and reviewed by 2,729 different laboratories confirmed that COVID-19 adult patients who were treated were members of underrepresented groups. According to research, knowledge of the primary purpose of making gains to health concerning the possibility of unintended consequences is still an ethical and cultural issue (Bhopal, 2008). In public health, many people were categorized differently based on age, race (ethnicity), underlying medical concerns, and whether or not they were housed. These findings show that the effects of COVID-19 on altered settings are extremely unequal (Wedge, 2020). According to the statistics, 44% of COVID-19 patients who were hospitalized were black, 30% were Hispanic, and 16% were homeless. Hispanic patients comprised 46.5% of those admitted to the hospital, much higher than the percentages for black patients (39.5%) and white patients (34.4%). According to the data (Quinn, 2021; Ndugga et al., 2022) collected during the study, most patients were older than 60.

Due to such information's prevalence, many African Americans hesitate to receive the COVID-19 vaccine. It has manifested itself in figures that reveal a gap in who is getting shots in our country, with white individuals accounting for 60 percent of those shots and African Americans accounting for fewer than 6 percent (Quinn, 2021; Ndugga et al., 2022). The history of the United States Study of Syphilis, which caused Black men in Tuskegee, Alabama, to suffer and die from the fatal disease (Quinn, 2021), is the source of people's mistrust in the medical system. According to Bhopal (2008), the concept of the scale of ethnic disadvantages and differences is the most essential and fundamental ethical pillar in the subject of ethnicity and health. These distinctions result only from strict adherence to ethical principles concerning equality, fairness, tolerance, and sensitivity toward people of color (Bhopal, 2008). Despite this, there is a widespread fear that health professionals' improper education and lack of ethical conduct are at the base of the COVID-19 outbreak (Ndugga et al., 2022). The Boston Medical Center (BMC) study offers statistical analysis of the clinical observation. On the

other hand, because of the context in which the study's observations were made, it does not analyze the cognitive reaction to a behavioral problem.

A topic that is at the forefront of a significant number of high-profile political discussions in the United States of America is the provision of people with a healthcare system that is fair and equitable and that allows access for all. Throughout history, underrepresented groups in test populations have typically not been given the consideration and attention they need. This is owing to a long-standing history of unethical procedures in early American medical trials, such as the Tuskegee Syphilis Experiment (Elliott, 2021). These experiments included the Tuskegee Syphilis Experiment. The Tuskegee Experiment is still considered one of the most prominent examples of African Americans being exploited as subjects in medical studies constructed around establishing a race-based classification system among people (Elliott, 2021). [Citation needed] [Elliott, 20221]. Not only did those who mandated this study lack moral sensibility, but they also had little respect for the cumulative impact of their actions. The study, which was conducted under the guise of treatment for "bad blood," was not only a misrepresentation of its true intent; moreover, the fact that it failed to provide medical treatment to its participants by, among other things, subjecting them to placebos, unwarranted procedures, or other non-therapeutic treatments, frequently resulted in a death that was extremely painful and unnecessary (Alsan & Wanamaker, 2018).

Furthermore, in addition to the deaths of individuals who were initial test subjects, many of their wives and children had been infected. This demonstrated that the degree of deception was grossly overestimated, which resulted in widespread harm (Alsan & Wanamaker, 2018). The Tuskegee syphilis research represents the amount and duration of deceit and mistreatment, which often proves to be founded in racism and cognitive dissonance. This study was conducted in the 1930s. The history of medical experimentation and abuse within medical research and the healthcare infrastructure has systematically exploited African Americans for over four centuries, resulting in a legacy of medical mistrust from minority communities (Alsan & Wanamaker, 2018). This has been done to exploit African Americans, leading to a legacy of medical mistrust from minority communities. The practitioners would have had the opportunity to assess the effects of their activities and reflect upon the worth of the study in order to compare it to the damage it inflicted upon the subjects if rigorous and enforceable ethical criteria had been implemented.

Problem Statement

According to the statistics, there is a significant gap between individuals getting COVID-19 shots. It has manifested itself in data from the beginning of 2021, indicating a striking imbalance in who receives shots in this country, with more than 60% of shots going to white people and less than 6% to African Americans (Elliott, 2021). Researchers are increasingly confronted with the challenge of effectively incorporating communities in research that are not completely protected in recognition that communities are unique from individuals (Quinn, 2004; Ndugga et al., 2022). Academics and researchers must conduct investigational studies to establish ways to increase clinical trial participation and patient outcomes and alleviate issues affecting public health safety (Wedge, 2020). This study aims to provide insight into why African-Americans were initially reluctant to get the COVID-19 vaccine and only participated in small numbers of clinical trials by conducting a historical exploration of what occurred with the Tuskegee experiments. Additionally, this study aims to make those focused on engaging African-American communities more knowledgeable and self-aware as they develop strategies to treat African-Americans or get them to participate in clinical trials.

The Lack of Completeness in the Research

Based on information from the Centers for Disease Control and Prevention (CDC), Ndugga et al. (2022) hypothesized that 78% of the total population in the United States has been given at least one dose of a COVID-19 vaccination. Notwithstanding this, as of July 11, 2022, throughout the 36 states for which a total vaccination rate could be computed by race or ethnicity, 87% of Asian people, 67%

of Hispanic people, and 64% of White people had gotten at least one dose of the COVID-19 vaccine. This rate was higher than the rate for Black people, which was 59% (Ndugga et al., 2022). Statistics show that individuals of color, including African Americans and Hispanics, are still less likely than their white counterparts to have been vaccinated during the vaccination rollout (Ndugga et al., 2022). This represents a gap in research that needs to be filled. The purpose of this study is to provide additional evaluation into the long-standing potential ethical and cultural leadership implications affecting public health concerns amongst minority populations.

METHOD

A content analysis of the techniques built from the research literature makes up the methodology. The objective is to take several points of view and include them in a single conversation that is exhaustive and pertinent, taking into account the most recent developments and insights. Tuskegee syphilis experiments, medical ethics, bio-ethics, informed consent, African-Americans and COVID-19 vaccinations, and African-Americans clinical trials are some keywords used in the search.

Aspects of Research That Have to Do with Societies and Communities

According to Yearby (2018), a problem currently at the center of political debates in the United States of America is providing residents with a fair healthcare system and equal access for everyone. According to the Agency for Healthcare Research and Quality (2018), access to healthcare can differ in the United States depending on a person's color, ethnicity, age, gender, socioeconomic level, handicap status, sexual orientation, gender identity, and home location. This is true regardless of whether the individual is male or female. According to the Agency for Healthcare Research and Quality (2018), ensuring that our underserved populations have access to a culturally diverse healthcare system improves healthcare access, satisfies unmet health needs, decreases preventable disease, and lessens these individuals' financial constraints. To guarantee that people of various racial and ethnic backgrounds receive individualized medical care, it is necessary to provide culturally competent healthcare and to conduct culturally inclusive healthcare research (Dawes, 2019). According to Dawes (2019), this type of care needs to emphasize innovative methods of illness prevention in addition to efficient medical treatments. Therefore, providing healthcare to everyone will only be feasible if a wide variety of research candidates are considered throughout the entirety of the healthcare research process. To be more specific, clinical research studies have to keep up with the changes in population diversity to give scientific evidence that healthcare treatments are effective across various ethnic groups.

According to research done by Durant et al. (2014), people who identify as members of a minority tend to be more hesitant about participating in clinical trials. According to Hamel et al. (2016), many research recruitment techniques have been implemented to increase minority participation in healthcare and pharmaceutical research. Even with these measures, there has been only a slight improvement in the recruitment of members of minority groups (Oh et al., 2015). As a consequence of this lack of diversity in clinical trial participation, large minority groups of United States citizens either receive medical treatment that has not been sufficiently examined or are placed at risk for healthcare consequences as a result of medications and treatments that are ineffective.

Compared to the number of white people who have participated in the research, the number of people of color who have signed up to participate in clinical trials in the United States has been declining statistically significantly. According to Clark et al. (2019), even if the percentage of minorities in the population of the United States is growing, less than 10 percent of patients who participate in clinical trials are minorities. Ramamoorthy et al. (2015) looked at 167 new chemical compounds approved by the FDA in the five years between 2008 and 2013. Based on their findings, they estimated that one out of every five of these medications has different response rates for different racial and ethnic groups. As a result, there is still a persistent demand for people from underrepresented groups in clinical studies.

Fear of ill-treatment, mistreatment, the unknown, and major pharmaceutical corporations, physicians, and healthcare institutions have been widely examined as obstacles to the participation of minorities in clinical trials (Blume, 2016; Clark et al., 2019). Studies have shown that these fears can prevent minorities from participating in clinical trials. According to one study (Clark et al., 2019), a significant factor in the underrepresentation of minorities in clinical trials is the anxiety associated with the prospect of serving as a “guinea pig” or subject in an experimental study. According to Farr et al. (2015), the historical maltreatment of minority individuals, convicts, and military members has resulted in a bad perception of clinical research on ethnic groups that will not go away. On the other hand, evidence reveals that these potential minority research candidates might consider participating in research if their physicians question them (Hamel et al., 2016).

According to Polite et al. (2017), increasing diversity in clinical trials by recruiting volunteers from a wide range of ethnic backgrounds leads to advancements in disease research, increased quality of care for all patients, and reduced racial and ethnic inequities. Studies conducted in the past have shown that underrepresented groups have a lower participation rate in clinical trials (Martin et al., 2011). According to Colby and Ortman (2015), in only a few short years, the population of the United States will consist of a “Caucasian minority,” and by the year 2045, this will be the case. According to the findings of a recent study (Haley et al., 2017), researchers have identified that an increase in the participation of minority groups in clinical trials is an urgent necessity. Most American citizens believe more research is necessary to advance disease treatment and prevention. According to Saultz et al. (2015), Americans anticipate receiving the most effective and scientifically sound preventative treatment and therapy for the disease. According to research, most people in the United States would be prepared to participate in research if asked, even though most people do not regard clinical trials as a form of health care that is suitable to consider personally. According to Garza et al. (2017), some people do not believe that their involvement in clinical trials will affect medical care in any way. According to Munro, Holmes, and Ward (2005), “Although researchers, policymakers, and local authorities may all work to enhance the well-being of vulnerable groups, it is possible that they may well have different perspectives which frequently affect and occasionally undermine the research process,” (p. 1025). This is a fundamental problem, particularly concerning the gatekeeping of information connected to the identity of study participants and the amount of engagement that the agency or the professional considers adequate.

Furthermore, according to Munro, Holmes, and Ward (2005), perceptions of the bounds of confidentiality and informed consent frequently conflict with parts of the research endeavor and the significance of the project. Minority communities, low-income populations, and populations with lower education levels are examples of vulnerable groups. Sutton, Erlen, Glad, and Siminoff (2003) found that in a previous study with vulnerable groups, many participants perceived research involvement as a pleasant experience and related this with being allowed to tell their stories. Research has also revealed that participants believe that by choosing to participate in the research, their narrative may help others; nonetheless, they are scared due to a history of maltreatment directed toward specific communities (Cooper, 1999). When planning this study, one of the most important considerations was striking a healthy balance between the potential risks of participation and the potential benefits of the investigation to society and the people who volunteered to participate. There was a discussion on the Belmont Report published in 1979 by the NCPHS. The participants in a study have the right to decide whether or not they want to participate in the research being conducted. This is one of the fundamental human rights stated in the Belmont Report.

Study of the Ethical Implications of the Tuskegee Experiment

The Tuskegee Syphilis Study (TSS) was a watershed moment in the progression of ethical standards for scientific research in the United States. In 1932, the historical syphilis study of Tuskegee involved the enrollment of six hundred African American men into a medical treatment program for “bad

blood.” Of these six hundred individuals, close to four hundred had previously been infected with syphilis, but they remained uninformed of such a population (Mandal et al., 2011).

The United States Public Health Service (USPHS) initiated a research study on the lethality of syphilis employing African American men from Macon County, Alabama, as public research human subjects. The finances for this project came from an endowment established by the Julius Rosenwald Foundation. Tuskegee Institute in Alabama was the location of the research that was later referred to as the “Tuskegee Study of Untreated Syphilis in the Negro Male” (Tuskegee University National Center for Bioethics in Research and Health Care, n.d.). This study was conducted on the grounds of Tuskegee University.

Although each participant in the study received a medical examination, they were never informed of the objectives or goals of the research (Nichols, 2011). However, they were all allowed to participate in the study. In the fifteenth year of the research, penicillin was discovered to be an effective therapy for syphilis and became widely available; nevertheless, the Tuskegee subjects were never allowed to get this medication in any way (Nichols, 2011). To add injury to insult, the researchers who designed the study told the physicians treating the subjects, who had reason to believe that their patients had become infected with syphilis, that they could take no action of any kind to help them (Mandal et al., 2011). The significant ethical violations involved with this study provided evidence of the potentially devastating long-term repercussions that racial profiling in medical research can have on a population. It is possible that this study would never have grown exponentially as it did if the population of the study had not been African American males during a time of racial dissension in our country. This is a possibility that can be considered. Beginning in 1932 and continuing until 1972, when it was finally terminated, the Tuskegee Syphilis Study was carried out. The research was conducted in Macon County, Alabama, which is located in the state of Alabama. At the time of the study, Macon County had a predominantly black population (84.5%) and high rates of low income and illiteracy (TSS et al., 1973).

To “follow and study the disease over a long period of time (1973),” the study recruited 399 Black men with late latent syphilis and a control group of 201 men without syphilis. In order to recruit and keep them in the study, the men were told they were being treated for “bad blood,” which is a colloquial term for syphilis as well as other ailments (Brandt, 1978). Spinal taps were performed to diagnose, but the procedure was marketed to the men as a “special free treatment” (Brandt, 1978). The guys were not given penicillin, although it was discovered in the early 1950s to be an effective therapy for syphilis and became accessible about the same time. They were provided with a placebo or some other non-therapeutic treatment instead. In at least one instance, treatment was withheld from affected males to ensure the continuity of the research (TSS et al., 1973). In addition, to guarantee access to the deceased men so that an autopsy could be performed, the USPHS offered to pay for the men’s funeral costs, but they refrained from disclosing the reason for their offer (Brandt, 1978).

Even though study results had been published more or less regularly beginning in 1936, the tale only became widely known in newspaper articles that appeared in July of 1972. An ad hoc committee was constituted by the Department of Health, Education, and Welfare in August 1972. This committee concluded that the study could not continue in its current form since it did not adhere to ethical standards. Those who had survived the event, along with anyone else who might have been impacted, were going to be treated right away, and a national committee was going to be established to monitor research on human subjects (1973). Following filing a class action lawsuit in 1973, the Tuskegee Health Benefit Program was established to offer the research participants lifetime medical treatment and funeral and burial services. 1975 was the year that participants’ family members first became eligible for benefits (CDC, 2011).

In 1979, “The Belmont Report – Ethical Principles and Guidelines for the Protection of Human Subjects of Research” was released by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, founded in 1974 (NIH, 2008). Following the recommendation of the Tuskegee Syphilis Study Legacy Committee (1996), President Clinton issued a public apology

to survivors of the Tuskegee study and their families on May 16, 1997. He also set in motion the establishment of the Tuskegee University National Center for Bioethics in Research and Health Care and the President's Council on Bioethics (CDC, 2011). Both of these organizations are currently in operation.

Infractions of Ethical Standards

According to Mandal, Acharya, and Parija (2011), the ethical violations involved with the Tuskegee Syphilis Study lasted for forty years and harmed a sizeable section of the community. According to Nichols and Leonard (2011), one of the most fundamental ethical principles was missing from the Tuskegee study. This principle, known as the duty of healthcare practitioners, to give a viable benefit to patients, is a core ethical principle. The participants, their families, and the general community were all subjected to long-term suffering due to the experiments conducted at Tuskegee. TSS researchers concealed the newly found syphilis treatment of penicillin in 1943 (Stebbing & Bower, 2004), although a public health law was adopted in 1943 (the Henderson Act) mandated testing and treatment for venereal illnesses. Researchers gave a list of research participants to local physicians and made an unethical request that TSE men not be treated with penicillin for syphilis. The local physicians erroneously cooperated with this request (Devettere, 2010). The International Nuremberg Code was established in 1947 as a response to the unethical atrocities inflicted on humans during World War II. This code noted fundamental principles that must be considered to satisfy "moral, ethical, and legal concepts in the conduct of human subject research" (National Institutes of Health, 2008, p. 5). In response to these atrocities, the Nuremberg Code was established. Even if the Nuremberg code was being followed, the TSS continued to engage in unethical practices. According to Stebbing and Bower (2004) and Torke, Corbie-Smith, and Branch (2004), participants in the TSS were not allowed to provide informed consent, although the Declaration of Helsinki issued in 1964 by the World Health Organization demanded informed consent for all human studies.

One other ethical issue that arose as a result of the research was the absence of participant agency. According to this guiding principle, the ability of the patient to make an informed decision voluntarily should form the basis of the decision-making process in healthcare (Nichols & Leonard, 2011). In the Tuskegee study, the researchers did not consider this concept as they exercised their autonomy and wants in treating patients who readily imagined they were obtaining valid and honest medical services (Nichols, 2011; Nichols & Leonard, 2011). As a result, the researchers deceived the patients into believing they received valid and honest medical services (Nichols, 2011; Nichols & Leonard, 2011).

During the Tuskegee research, the principle of non-maleficence, which states that no damage should be done to patients or subjects, was grossly disregarded. The researchers intentionally withheld a treatment known to be safe and effective from the people who participated in the study. This infringement is connected to another principle that reflects the importance of researchers being honest in dealing with all the people who participate in studies; it is a dovetail. As a technique of implementing fair practices among all individuals, justice was violated indiscriminately in the Tuskegee research from when a viable cure for syphilis was discovered and made available (Nichols & Leonard, 2011). Justice can be understood as implementing fair practices among all individuals. During the Tuskegee study, the ethical ideal of veracity, best described as the telling of the truth, was undermined due to the clear lack of complete disclosure on the side of the researchers to the participants on the expectations of the study. At no point throughout the development of the trial did the researchers provide complete disclosure of their intentions or of the treatment once it became available. In addition, the researchers did not consider the principles of individual respect and a person's right to know concerning informed consent (Nichols & Leonard, 2011).

Regard for Individuals: The people who took part in the TSS were not considered autonomous beings with the right to decide for themselves. Instead, it was determined that the men lacked the intelligence required to seek treatment for their disease or to comprehend what was being done to

them in the study or what was not being done to them. Not only were the participants provided clear explanations about the tests and treatments, but they were also intentionally bullied and misled into participating (Brandt, 1978). This was done in order to ensure that the results of the study would be favorable.

Justice: It is self-evident that the limitedly educated, low-income men forced to participate in the TSS were selected because of their racial and social class. After an effective cure for syphilis had been developed, refusing treatment to those who participated in the trial was unethical. Since the men were not treated, the community's overall health was jeopardized (Brandt, 1978).

Issues Relating to the Profession: It is now becoming clear that medical professionals, the United States Public Health Service, and the National Institutes of Health were complicit in violations of the rights of human subjects before publishing the Belmont Report. In October 2010, the United States of America apologized to Guatemala for the deliberate spread of syphilis among Guatemalan jail inmates (McNeil, 2010). (2010), Rebecca Skloot provided information regarding the usage of tissue removed from a poor African-American lady in the early 1950s without the woman's knowledge or consent. According to research published in 2004 by Lerner, 22 patients at the Jewish Chronic Disease Hospital in Brooklyn were given cancer cell injections without knowledge in the 1960s. Given the current knowledge, it is impossible to fathom how the experts involved in these incidents could have reasoned their actions.

Henry Beecher, a professor at Harvard, presented his exposé on 22 incidents in 1966 (Lerner, 2004). These cases demonstrated apparent violations of ethical research standards. In his essay, he offered pointers and suggestions to researchers in the medical and scientific fields, encouraging them to exercise greater awareness in their work. Nevertheless, it would appear that, despite the public outrage that was caused by Beecher's evidence, the formal accusation of physicians and administrators at the War Crimes Tribunal in Nuremberg, and the subsequent creation of the Nuremberg Code in 1947, research ethics were not well developed until after the TSS had been terminated. It was not until 1974 that the National Research Act was made into law, and not until 1980 that the American Medical Association incorporated a provision for protecting human subjects in its Code of Ethics (American Medical Association, n.d.). Both events occurred after the National Research Act was enacted in 1974. Allan Brandt (1978) suggests that the nurse who participated in the study, Eunice Rivers, was unaware of the potential adverse health implications that the study could have on the people who took part in the study. Although the current American Nurses Association Code of Ethics (2001) references the concepts of respect for human dignity and patient right to self-determination, it is improbable that those ideas were imparted during the TSS years.

Transgressions of Ethical Codes Committed by Healthcare Professionals

Following information from the American Medical Association (AMA), published in 2011, the code of ethics for physicians and other medical workforce members includes a clause specifically related to patients' treatment, care, and involvement in the medical relationship. The American Medical Association (AMA) (2011) requires that all proposed experiments be subject to an ethical evaluation by a human studies board before moving forward. The historical beliefs of bioethics demonstrate medical science's acknowledgment of atrocities such as the Tuskegee study. These concepts also describe a commitment to evolve from a paternalistic paradigm to a patient-centered, individualized decision-making process founded on informed consent. According to Slavicek and Forsdahi (2009), the period during which the Tuskegee research was conducted is illustrative of our country's challenges historically with racism, sexism, and the acknowledgment of the fundamental dignity of all populations. The Tuskegee study and other atrocities committed against humans have led to establishment of institutional review boards and global requirements that specify the parameters of human research. These developments speak to the necessity of correction in medical research.

Models for Making Ethical Decisions

Even if the damage caused by the Tuskegee study may never be undone, it is essential to comprehend the factors that led to its occurrence. For those working in healthcare or research, deciding in the face of an ethical conundrum can be challenging and frustrating. According to Swisher and Davis (2005), using an ethical decision-making model that specifies a predetermined order of actions might help comprehensively review all aspects of a situation before deciding how to proceed. Several writers (Gabard & Martin, 2003; Greenfield & Jensen, 2010; Swisher & Davis, 2005) have devised decision-making models that can be applied in several settings. Remembering restrictions could be present in any model, regardless of whether a framework is chosen to guide decision-making. For instance, Swisher and Davis (2005) point out that it might be difficult to adequately account for relational and emotional considerations in decision-making models when dealing with ethical challenges; as a result, ensuring that any concealed values, biases, and consequences are unearthed during the reasoning and decision-making process (Greenfield & Jensen, 2010; Swisher & Davis, 2005).

According to Stone (2002), the maltreatment of human subjects in the Tuskegee Experiment may have been prevented if an ethical decision-making model had been utilized prior to the experiment's execution to examine the design and potential ramifications of the Tuskegee Experiment. If the decision models associated with patient-centered care and quality improvement programs had been in place when the Tuskegee research was conducted, the occurrences could have been averted, or their severity could have been lessened. According to the foundations of such models, research must move away from a utilitarian approach and toward a humanistic approach, which considers a subject's right to consent, fairness, and honesty through full disclosure (Miles & Mezzich, 2011). The expectation that all patients would be cared for by medical professionals respectfully and morally, giving precedence to the requirements of the person seeking medical aid, has been widespread worldwide in recent decades. To analyze this situation and the overarching ethical principles at play, it is essential to consult a tried-and-true framework to facilitate the decision-making process. In order to provide the conceptual framework that would guide the rationale for issue-solving in this conundrum, the Kantianism theory has been proposed. According to Hemmings (2006), the foundation of Kant's theory is that an individual must behave in a way that is both compliant with their obligations and following what is required of them morally. The researchers at Tuskegee violated the standards of Kantian bioethical decision-making disrespectfully. Specifically, they rejected the principles of informed consent and right-to-know of the persons who participated in the study. According to Hemmings (2006), the credibility of the research design can be improved by ensuring that patient self-determination, informed consent, and an infusion of quality care are present throughout all human investigations.

According to Devettere (2010), the study of bioethics is founded on the moral duty principles that protect the rights to autonomy, beneficence, and justice (the three precepts of the Belmont Report) and the principle of non-maleficence. The Nuremberg Code, an international standard for research on human subjects, includes ten directives that represent these ideals and unquestionably could have been applied to the TSS as early as the 1950s (National Institutes of Health, 2008). These directives mirror the concepts that underlie the TSS. There were a few different models that the researchers and staff of the TSS could have used, and those models could also serve as guides for future studies. The first is a model of moral reasoning known as the four-component model. The following are the steps that are included in this model: 1) Moral sensitivity, which assists in the identification of conflicts and considers all interested parties, the consequences of the study, and any obligations to the subjects; 2) Moral judgment, which includes the process of justification for conducting the study; 3) Moral commitment, which considers the researcher's responsibility to the subjects; and 4) Moral action, which determines the most appropriate action to be taken. (Rest, 1979).

Another model is the reflective equilibrium approach, which could have been used as an ethical decision-making model by testing beliefs in 1) The Liberty principle, which requires ensuring that all participants have an equal right to basic liberties (Rawls, 1999), and 2) The Difference principle,

which requires ensuring that all social and economic inequalities give the greatest advantage to the least advantaged (Daniels, 1996).

According to Jonsen et al. (2002), the Four-Boxes technique considers not only the medical indications but also the quality of life, patient preferences, and the contextual characteristics of the study. In clinical research, it is critical to consider each of these issues. A more recent model would have worked better as an ethical decision-making paradigm. The Medical Ethical Reasoning Model is an approach that integrates different ethical and reasoning models into a single method. According to Tsai and Harasym (2010), it identifies the problem encountered, examines the possible diagnosis or choice in the process, recognizes commonality, seeks information and data, plans and manages the project, determines the outcome indicator, and builds a basis for justification.

Beemsterboer (2010) presented a model with a six-step process, which contains the following steps:

1. The first and most important step is determining the ethical dilemma or problem that must be addressed. Once an issue has been identified, the person making the decision must explain the ethical dilemma in a manner that is both clear and brief, but only after considering all of the essential parts of the situation. If it is already obvious whether anything is proper or wrong, then there is no need to proceed to step two.
2. Acquire Information In order to make an informed choice, the person making the decision must first acquire relevant information. This could contain new information about the issue as it becomes available, with the possibility that it comes from more than one source. It is necessary to have information regarding the values held by the various parties involved, such as those held by the patient and the healthcare provider. This stage is typically time-consuming since the required information might not be immediately accessible.
3. The next phase, which states the options, entails brainstorming to identify as many alternatives (or options) as is humanly possible. Another common error is the assumption that there is just one correct response to each given inquiry. This step compels those responsible for making decisions to examine the issue from every conceivable perspective to establish what stakeholders may consider potential alternate solutions.
4. Apply Ethical Principles to the Choices. This step involves looking at the issue with an emphasis on ethical principles (such as autonomy, beneficence, non-maleficence, and justice) and ethical notions (such as paternalism, confidentiality, and informed consent).
5. When in a position to decide because each option has been thoroughly discussed in terms of its benefits and drawbacks; as a result, there is a sound basis upon which to base the decision.
6. The final stage is implementing the decision, known as the implementation process. The unfortunate reality is that appropriate decisions are only sometimes put into action. The decision to do nothing communicates an implicit endorsement of the current state of affairs.

Codes of Ethics Governing Professions

According to Scholl (1981), the application of codes, regulations, guidelines, and other systems that aim to define particular behaviors or means, which are immoral, is another essential ethical standard. These standards can be found in various forms. These culturally developed and disseminated codes of conduct or ethical systems contain lists of actions that should and should not be taken by members of society. They also serve the job of maintaining a balance of power and protecting those who are helpless. From a social psychology point of view, these ethical codes function like other process-based control systems, such as state laws, corporation rules, policies, or societal norms, in the sense that they are imposed through both external and internal means. In the case of the Tuskegee experiments, medical experts, researchers, and professionals working in public health who were aware of the study broke their respective fields' rules of professional ethics. Penicillin, a medicine known to heal the

condition, was withheld intentionally and in error by these individuals. Upholding the reliability of the research was the reason for doing this. According to Devettere and colleagues (2010), knowingly waiting for the signs of syphilis to appear is the same as purposefully inflicting harm on the patient. In addition, the researchers purposefully did not inform the patients about their condition, or the procedure followed in the investigation. They did not disclose that they were investigating and treating syphilis; rather, they told the patients they were investigating and treating “bad blood.”

According to Kampmeier (1972), additional medical professionals who were not directly involved in the study but were aware of the research and the potentially deceptive information provided did not administer treatment to the participants. Models of Decision-Making Capacity can be used to assist in determining whether or not patients have the ability to make particular decisions. In order to obtain reliable information regarding the patient’s capacity for making decisions, it is necessary to carry out all three of the following general steps. According to Devettere (2010), the three stages that should be completed are Understanding, Evaluations, and Reasoning. During the phase devoted to comprehension, the investigators had to have informed the patients about syphilis and inquired about the advice of medical professionals. These TSS participants should have been able to receive suggestions from attending physicians or other medical professionals who should have been present. This would make it possible for the patient to receive complete information regarding the dangers and advantages of the study and then move on to the evaluation stage. After that, the patient controls their treatment and can choose the option they believe is in their best interest and determine the most appropriate next step.

Nevertheless, specific circumstances call for providers to make decisions on behalf of participants. One example would be providing a patient with a mental illness with medication to stabilize them. The Reasonable Treatment Standard is another method that can be utilized to arrive at ethical conclusions (such as the one that pertains to a patient with a mental illness). The reasonable treatment standard does not utilize the substituted judgment and best interest criteria. Over and above a specified baseline of syphilis symptoms, the patient in the TSS would have needed to be treated by the participating physicians at some time throughout the study.

Impacts It is possible to refer to ethics as “the study of values and moral behavior,” and “ethical behavior” is defined as “acting in ways consistent with one’s values and the commonly held values of the organization and society,” (Nelson & Quick, 2008, p. 107). This entails incorporating personal and social factors as criteria into organizational decision-making processes and decisions regarding behavioral options. These definitions of ethical behavior focus on a decision’s impact on others. The concept that it is unethical for an organization to make harmful decisions to one or more of its stakeholders underpins this stakeholder-based approach to problem-solving. This is especially true if the key stakeholders are helpless or think they are “at the mercy of the decision makers” (Nelson & Quick, 2008). One of the more stringent standards in this category states that people should try to avoid causing others damage and assist others.

One question that has yet to be resolved is whether or not the TSS was responsible for the current lack of trust in medical research that is prevalent in the African American community. It is a persuasive argument that Brandon, Isaac, and LaVeist make (2005) that the TSS is not the cause of the increased possibility of African Americans declining to participate in medical research and donating organs. Instead, “broader historical and personal experiences” cause this increased likelihood. Because our nation does not have a health care system that provides equal access for all, vulnerable populations suffer more from disease than those with higher incomes (World Health Organization, 2000). This results in trust and a need for more participation in studies that could benefit those vulnerable populations. While Institutional Review Boards are responsible for protecting the rights of persons, broader concerns regarding the rights of communities have been noted in connection with the conduct of research (Shore et al., 2010).

CONCLUSION

The content analysis of the relevant literature shows many key aspects that have the potential to be beneficial in assisting more African-Americans in being more active in clinical trials and less reluctant when new vaccines become available. These recommendations consist of the following:

1. Partnering with minority primary care physicians that have solid relationships with minority patients. A major obstacle to participation is establishing trust and gaining access to minority individuals. They are more willing to trust others on a team with someone who shares their cultural background. These relationships ought to include training and education programs for minority physicians to address the clinical trial work being done at the center, how to have patients participate, and the benefits of advocating for clinical trial participation by minority patients. If a physician has an established working relationship with the hospital or university running the clinical study, they are more likely to refer patients to participate in the clinical trial.
2. The importance of communication and engagement with the community cannot be overstated. Building trust also requires communicating in a way that is open, honest, and sensitive to cultural norms. Instead of trying to persuade minority people to participate, involve them in activities that make them feel welcome so they will want to join.
3. Eliminate obstacles that could prevent people from participating or provide help to make participation easier for those who do join. One of these obstacles could be the requirement to have access to transportation or childcare services for an extended period to participate. Other measures include meeting with prospective participants and talking to them over the phone before their clinical appointments. Having staff members on hand to assist with health literacy and answer questions raised by patients as a research nurse discusses the trial and guides patients through the completion of consent forms is essential.

Clinical healthcare practitioners are put in a position where they must make challenging decisions regarding their patients' care due to the rapid evolution of the healthcare environment. In certain circumstances, these options can become entangled in moral conundrums; in addition, the decisions that patients make for themselves might not agree with what their families or clinicians believe should be done. Even among people who seem to be very similar to one another, totally divergent value systems may emerge. As clinical research remains an essential component of medicine, those working in medicine are being asked to tackle more difficult problems.

The commercial and government organizations sponsoring research initiatives expect results, and this pressure frequently results in either unethically managed or completely fabricated studies. Those participants who have the misfortune to be included in these studies have a much-increased chance of obtaining either insufficient or no treatment. Exploring the Tuskegee Experiments in this context provides professionals working in public health research with a framework for understanding the predominant ethical theories and principles used in health care, determining any legal and regulatory implications, and working in collaboration with their colleagues and patients/clients to make effective decisions that determine the appropriate course of treatment or refusal of such, for and with those for whom they care. The Tuskegee syphilis experiment is still widely regarded as one of the most egregious examples of disdain for ethical values and maltreatment of those principles. When patients were not given the penicillin available, it was obvious that the principle of respecting human dignity had been breached. A comment made by the Director of the

Venereal Disease Unit for the Public Health Service, John Heller, revealed a clear lack of respect for the people who took part in the study. Heller said that "the men's status did not warrant ethical debate." According to Jones (1993), "They were clinical material, not sick people; they were subjects, not patients." The fallout from the protests in response to the Tuskegee Syphilis Study can still be experienced today. Researchers are now more conscious of the necessity of ethical decision-making

models when starting new research projects because human subject research must be approved by an Institutional Review Board (IRB). This has helped to reduce the number of unethical research projects that have been conducted. Before any protocols or documentation regarding informed consent may be sent to participants, they need to be drafted under the IRB's criteria and given the go-ahead for approval by the Board. Rules for the protection of human subjects in research should serve to prevent projects such as the Tuskegee Syphilis project and safeguard people from being exploited in the name of scientific inquiry. These goals should be accomplished by preventing such programs as the Tuskegee Syphilis Project.

If the researchers had used an ethical decision-making model, they would have been better equipped to make ethical, legal, and moral decisions. If the researchers had framed the experiments in a principles-based approach, they would have found that the study violated the fundamental ethical principles of beneficence, non-maleficence, fairness, and autonomy. The researchers would have revealed this. A rights-based strategy could have avoided the need for the forty-year study or decreased its duration.

In the Tuskegee experiments, fundamental human rights such as the right to choose freely, the right to human dignity, the right to truth, the right to what is agreed upon, the right not to be damaged, and the right to privacy were all disregarded (Velasquez et al., n.d.). Basic human rights, such as human dignity, were also disregarded. It might have been easier for the nurse to opt out of taking part in the research of the men if a care-based model had guided her. According to the American College of Obstetricians and Gynecologists Committee on Ethics (2007), a caring model frames decision analysis in a way that makes decisions regarding empathy, compassion, caring, and love possible. Although the Tuskegee Syphilis Experiment took place a century ago, the repercussions of the study are still very much relevant today. The shortcomings and mistakes throughout the research have provided the basis for changes urgently required in the academic research community. As a direct consequence of this, the government of the United States has enacted laws and regulations to prevent the further exploitation of vulnerable populations, ethics models and approaches have been developed to assist researchers in their studies, and institutional review boards have been established to monitor and oversee human research. Research can be carried out ethically and beneficially if the appropriate models and principles are followed (Biasetti & Mori, 2021). In order to maintain the credibility of their work, researchers should reflect on and apply the knowledge gained from unsuccessful studies such as the TSS.

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