

U.S. Syphilis Study at Tuskegee and Minority Participation in Research

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By Mackenzie Riggs

Setting the Scene

Many nights after finishing my shifts of running entrees, pouring wine, and remaining unwaveringly hospitable, I would sit at the gleaming wooden bar centered in my restaurant of employment and chat with the manager, Mario. Over glasses of Bogle Merlot (the best tasting red wine for its price), we would avidly avoid talking shop or anything restaurant and would discuss more irrelevant topics like travel, World War II, and the ingenuity of *Jersey Shore*. A young, white woman in her tender young adult years, such as I, and a middle-aged black man, such as he, had many dynamics and opinions to share, and the learning was immense and relentless.

One late night at the bar, the discussion turned medical, and Mario confessed that he distrusted and avoided doctors until an illness turned frightfully dire and swore that he would never, never, ever, ever participate in a medical study. At that time I was in the hub of the hurricane that is 6th semester of nursing school with pre-planning, informed consent, patient-care, ethics, error reports, and 6,000 page lectures turning violently in my naïve novice-nurse's head. The shock of such a distrust of medical professionals who slave through years of school to become proficient providers for patients nearly knocked me off the barstool and on the linoleum.

"Why?" I asked, wide-eyed.

"Have you ever heard of the Tuskegee study?"

Introduction

The U.S. Syphilis Study at Tuskegee studied the condition and progress of nearly 400 African-American males with diagnosed syphilis. Lured to the hospital with promises of free transportation, lunches, medical care, and burials, the subjects were observed for nearly 40 years and never informed of their condition. These subjects also were never notified of their participation in a research study, and, though efficient syphilis medications were available, they were not administered treatment. The study also included another 200 syphilis-free subjects who were used as the control population. These subjects were falsely diagnosed with "bad blood" and ordered to receive periodic and invasive medical examinations (Chronicle, 108).

Because officials of the Public Health Service deemed the Tuskegee Syphilis study ethical and possessive of scientific value, the public and most medical professionals were blindsided by how such an overtly harmful study was allowed to continue for decades. The Nuremburg Code of Ethics, which established ethical standards for all subsequent research studies following the dastardly Nazi medical experiments during the Holocaust, had provided the public with confidence in the respectful and moral treatment of participants in research and experimentation. The Tuskegee study, however, undermined the established standards of informed consent, autonomy, nonmaleficence, and other expected ethical principles. It created much distrust about research

participation, especially in the male African-American community that was clearly targeted in the Tuskegee study.

This study conjures countless discussions of ethical dilemmas, racial inequality, and respect for life. In addition to the initial participants who were severely harmed by the Tuskegee study, several generations of minorities will be harmed by their justified mistrust in the beneficence of medical professionals and research studies. African-Americans and other minorities are now underrepresented in medical research studies for the development of new medications and treatment (Scharff et al., 2010). As a result of the Tuskegee studies, many African-Americans possess much skepticism about research participation and the practice of ethical standards, and this mistrust cannot be eliminated until racial disparities are confronted and cultural competency is acquired by all medical professionals.

Catheterization without Representation: The Significance of Equal Participation in Research Studies

In 1990, the U.S. Department of Energy and the National Institutes of Health funded researchers with the resources to complete the Human Genome Project, which identified the 25,000 genes in human DNA, sequenced the 3 billion chemical base pairs, and stored the information into databases. When the project finished, researchers proclaimed that the DNA studies proved that no consistent gene patterns exist to distinguish one race from another in modern human beings. Race was scientifically proven to be a social myth conjured in the mind of the ever-chastising, ever-competitive human race (US Department of Energy, 2007).

Why, then, must research conductors recruit from a diverse pool of participants who reflect racial proportions when race doesn't even really exist? And why should organizations pledge millions of dollars to fund studies about how to minimize racial disparities? The reason stems from a combination of various alleles, a series of genes that can commonly occur within people who lived in the same region for generations, and various environmental factors, including socioeconomic status and family variants. This combination of genetic predisposition and ecological influences increases the risks for some "races" to acquire certain diseases and conditions. For example, African Americans possess an increased risk for presenting with sickle-cell anemia, hypertension, diabetes, strokes, and kidney failure (LeMone & Burke, 2008). This group, however, also displays lower participation rates in research studies concerning these exact conditions (Scharff et al., 2010). Therefore, in order to ensure efficacy, the treatments and medications prescribed for such conditions should be developed with consideration of genetic and environmental differences between "races."

While considering this concept, a Boston Tea Party metaphor stubbornly performs a dramatic reenactment behind my eyes. A wooden ship creaks into the harbor, its herbal cargo tempting progressive colonists with 6,000 pounds of fully-oxidized leaves and astringent flavors. Shortly after anchoring, dozens of angry colonists scale the ship, toss overboard tea crates into the sea, and, essentially, show the British Parliament their discontent with the status quo of "taxation without representation."

During the time the Boston Tea Party actually occurred, American colonists were forbidden to elect their own representatives to Parliament but, nevertheless, were still expected to mind British laws. Because the ideas and values of the British representatives did not synch with the colonists', a dependent settlement could no longer exist and the American Revolution erupted. Likewise, unrepresented African Americans are currently expected to comply with guidelines created by

research studies. Most medical treatments are tested for an overwhelmingly Caucasian subject population but are consumed by a startlingly different-looking population (McCallum, Arekere, Green, Katz, & Rivers, 2006). Because research participants do not accurately represent the populations, the variations between groups are disregarded and can result in detrimental adverse events.

Research

Research solidly suggests that the U.S. Syphilis Study at Tuskegee created a complex mistrust among African Americans regarding research studies and bioethics. McCallum et al. (2006) conducted an extensive literature review of studies concerning low research participation resulting specifically from the U.S. Syphilis Study at Tuskegee, and the results were considerable. Compared with only 11% of White males, 27% of African American males reported less interest in research participation and health promotion due to the U.S. Syphilis Study at Tuskegee. African Americans also were more likely than Whites (81% of African Americans versus 28% of Whites) to be knowledgeable of the study, and many of these individuals reported that their knowledge would influence their decision to participate in future medical research (46% of African Americans versus 34% of Whites). In addition, focus groups reported that the U.S. Syphilis Study at Tuskegee alone justified their mistrust in medical researchers, and the study was repeatedly cited as a “symbol” for the general wariness of medical research.

Brandon, Isaac, and LaVeist (2005) measured the relationship between awareness of U.S. Syphilis Study at Tuskegee and mistrust of medical care using a Medical Mistrust Index. Four hundred and one individuals participated in the study, and researchers discovered that 87.1% of the Tuskegee-aware African Americans believed that a similar study could happen again today. This study also revealed that a large majority of the participants learned false information concerning the study. Most participants, both black and white, believed the researchers at Tuskegee injected the men with syphilis, and another large portion believed that the U.S. Army conducted the study. As a result of the misinformation and wounded trust, African Americans display lower participation rates for controlled clinical treatment trials, intervention trials, and other various study types (Scharff et al. 2010).

Beyond Tuskegee

Though research has undoubtedly linked the U.S. Syphilis Study at Tuskegee to decreases in study participation among African Americans, many studies suggest that the general mistrust of research resulted from many other compounding causes. McCallum et al. (2006) illustrated this by reporting that African American participants who had no previous knowledge of the U.S. Study at Tuskegee were still less willing to participate in medical studies than those who had previous knowledge of the study. Therefore, to adequately promote participation in research trials, re-establish trust of the health field, and adequately serve the medical needs of all people, practicing medical professionals must scrutinize all existing barriers and look beyond Tuskegee.

Several researchers conducted studies that acknowledged the significance of the U.S. Syphilis Study at Tuskegee but also explored other barriers to study participation. Scharff et al. (2010) described results of several qualitative studies and cited low health literacy, limited access to health care, and negative interactions with health care providers as other causes of mistrust of the health field. The article reported that ethnic minorities received less information, empathy, and attention from physicians. It was also discovered that African-Americans were more likely to believe that researchers would use results to reinforce negative stereotypes about their ethnic group or expose them to new risks. Katz et al. (2008a) conducted an analysis of common perceived risks associated with participating in biomedical research. African American subjects reported that

minorities were more likely to be exploited and less likely to receive a thorough cancer screening.

Scharff et al. (2010) suggested that a lack of cultural diversity among hospital staff is a major contributor to the mistrust of health profession. My clinical experience alone supports this entirely; while charting in the glass-enclosed computer station, the hub of the pediatric floor, physicians, nurses, and occupational therapists will circulate through the room scanning documents, telephoning orders, secretly checking personal e-mails, etc. The types of people that enter that room are very diverse: Caucasians, Koreans, Indians, females, males, Russians, Pakistanis. But, where are the African-American members of the hospital staff? To find them one must walk through the hallways of the hospital. From my experience, African-Americans fill the patient technician and custodial positions and are usually seen recording vitals or mopping the floors.

It is unbelievably discouraging that African Americans admitted to similar hospitals will likely never have their care directed or even consulted by another African-American. Instead, it is probable that they will witness subtle displays of white society's dominance of the economy and the health care field. Mistrust of the medical profession is understandable when one imagines surrendering his or her health care needs to a profession that somehow deters African Americans from pursuing a health degree and providing care.

Studying Those Who Refuse to Be Studied: An Oxymoron?

Katz et al. (2008b), Brandon et al. (2005), and several other studies all claimed to examine the apprehensiveness of those who are disinclined to partake in research studies. But how can one recruit research participants who are truly unwilling to participate in research? The subjects of these trials are a population that clearly found some hint of value and safety in research studies and hence contributed much time and thought. Therefore, it is very likely that the most suspicious and frightened individuals (i.e. the most important individuals for these studies) were not studied and never will be studied. Would Mario, my manager, participate in a study about participation? This is both a random thought and research critique by Mackenzie Riggs, SN.

Change Proposal

Researchers studying the impact of the U.S. Syphilis Study at Tuskegee acquired a saturation of participant testimonies detailing an ingrained, lifelong mistrust of medical research. Many reported observing a mistrust possessed by both their grandparents and their grandchildren; such an embedded and trans-generational suspicion of the medical profession must be strategically counteracted. A significant number of studies regarding barriers among African Americans also offered specific suggestions of how to effectively disseminate the existing mistrust.

Based on the reports and testimonies of study participants, Scharff et al. (2010) prompted researchers to develop strategies to increase the likelihood of research participation among minorities. Suggestions included encouraging partnerships between medical organizations and community-based organizations serving the African-American community. These collaborations would bridge trust from community organizations to unfamiliar medical associations, and, thus, increase the effectiveness of health promotion and participation. For example, I believe that an effective partnership could exist between the Boys and Girls Club of America and the American Diabetes Association. Because the majority of children served at Boys and Girls Clubs are minorities, the American Diabetes Association could specifically encourage the early prevention of diabetes and simultaneously develop an atmosphere of benevolence between the medical community and African American families. In addition, minority children could retain lifelong memories of positive experiences with members of a medical organization. Another suggestion by Scharff et al. (2010) included delivering culturally targeted education programs, which would be

developed by members of the community. These education programs would be designed to consider cultural barriers and would deliver essential health promotion information to minority communities.

Research by Brandon et al. (2005) proposed that health care clinics and research facilities require completion of cultural competency training. The researchers suggested that the training programs focus on improving the overall experience of African-American healthcare consumers. If implemented carefully and adequately, these cultural competency training programs could improve the quality of care provided to minorities, re-establish the trust in medical providers and subsequently increase minority participation in research.

Summary

The U.S. Syphilis Study at Tuskegee and its severe violation of biomedical ethics and human dignity profoundly diminished the trust between African Americans and the medical community. As a result of the mistrust, African Americans are now underrepresented in medical research studies and causing the creation of treatments developed for a severely unrealistic Caucasian population. Researchers have diligently studied the barriers that prevent minorities from participating in research and concluded that interventions such as cultural competency training and culturally targeted education programs could improve medical-minority relations. I, however, believe that the best intervention is fervent, unabashed protection of human dignity. A renewed commitment to the Nuremberg Code of Ethics in the medical community and the promotion of a universal culture of respect could be the most important factor in creating and maintaining trust among all populations.

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