

**HISTORICAL ANALYSIS OF BIAS IN MEDICINE TOWARDS PEOPLE OF COLOR
AND WOMEN**

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Abstract

The history of unethical methods in medicine have led to the propagation of mistrust and fear in patients in the United States. This paper will discuss malpractice during Marion Sims' experimentation on black women to perfect his vesico-vaginal fistula (VVF) surgery technique followed by the Tuskegee Syphilis study which followed about 600 black men who contracted syphilis but were not treated with penicillin. The stigmas and stereotypes perpetuated through medicine impact not only people of color but also women due to a lack of representation of both groups in research. Using the framework of unintended consequences, this paper will analyze the effects of this longstanding history using case studies as well as the implementation of newer programs and studies aimed at these problems. This framework will be used to reveal how these programs have instead perpetuated the already-existing problems. New government programs meant to increase access (e.g. the Affordable Care Act) have instead become extra hurdles. This program was meant to help the uninsured or under-insured have access to equal care, but because healthcare systems receive less compensation from treating those covered under government programs, this has become an extra means to discriminate against patients.

Introduction

Remember those long videos that UVA makes us listen to at the beginning of every year? They make you watch a bunch of training videos and then do some word association activities. It seems long, boring, and kind of useless. However, the implicit bias videos are meant to force you to think about and tackle inner biases that you might not even know existed. The word association activity, particularly, targets positive and negative connotations that persist in your mind. In this way, they force you to evaluate the biases all around you. These biases have shaped so many important decisions from school district zoning to locations of supermarkets to how you are treated at the hospital. The lack of healthcare data about minority populations (specifically people of color and women) due to a history of biases, malintent, malpractice has created an environment of fear and distrust, which results in worse diagnosis and prognosis of patients.

In this paper, I will outline some events that have contributed to this history including Marion Sims experimentation on women (Holland, n.d.; Ojanuga, 1993) and the infamous Tuskegee Syphilis Study (Katz et al., 2008; *Tuskegee, Trust in Doctors, and the Health of Black Men*, n.d.). These events were selected because they clearly display actions that harm the groups of interest. Many of these practices were considered normal for their time periods, but constantly changing standards in the medical community and society have highlighted the need to retrospection. Next, I will highlight how current events continue to propagate the same issues from history in different ways. The paper will wrap up with a summary of current efforts trying to mitigate these issues and why they have not been effective using the framework of unintended consequences (Bruce Edward Tonn & Dorian Stiefel, 2018; Harrison et al., 2007).

History of People of Color and Women in Medical Contexts

Marion Sims, the father of gynecology, is well-credited for his work on a surgery for vesico-vaginal fistulas (VVF). This is a condition that occurs in women after birth where a tear forms between the bladder and vagina, leading to incontinence and leaking. Despite being a trailblazer, Sims' controversial decisions highlight many false beliefs. He perfected his technique through surgeries on three enslaved black women over four years (Ojanuga, 1993). One of the women, Lucy, was operated on without anesthetics as Sims incorrectly believed a popular opinion at that time about how black people cannot feel pain. When surgeries failed, Sims' controversial use of a sponge to drain the urine from the bladder led to Lucy contracting blood poisoning, leaving her sick for months (Holland, n.d.).

Furthermore, Sims failed to receive consent from these women. In fact, the medical and social system at the time recognized Sims as the legal owner of these women and the one who had the power to bestow consent in their stead. Additionally, some supporters suggest that because of the societal standards at that time and Sims' position as a white man, he should not be judged negatively for his actions (Holland, n.d.). However, other well-known doctors at the same time received informed consent from their all their patients. One example is Ephraim McDowell who operated to remove a large abdominal tumor from a white woman after receiving informed consent (Holland, n.d.).

The Tuskegee Syphilis study followed the lives of about 600 largely poor black males who had syphilis from 1932-72. Since the researchers' goal was to understand the progression of the disease, the men were never given the proper treatment despite numerous studies proving the efficacy of penicillin. Furthermore, the men were encouraged not to seek medical advice elsewhere and compensated through hot meals and burial expenses (Katz et al., 2008).

Following the end of the study due to public outrage, older black men in surrounding areas utilized medical care significantly less. One effect of this can be seen through the sharp decline in life expectancy for black men at the height of the medical distrust (*Tuskegee, Trust in Doctors, and the Health of Black Men*, n.d.). One study addressed whether knowledge of the Tuskegee Syphilis study reduced willingness to participate in other biomedical studies for whites and blacks. It determined that knowledge might have effects on people's willingness. Another study from the National Bureau of Economic Research found that mistrust spiked due to the lapse in ethics in response to news coverage of this study (*Did Infamous Tuskegee Study Cause Lasting Mistrust of Doctors Among Blacks? - The New York Times*, n.d.). However, since this study, lapses in ethics have continued to occur regarding the black community, further perpetuating the distrust (*Impact on Healthcare | Tuskegee University*, n.d.).

Women are consistently misdiagnosed. A majority of the healthcare information on disease progression and symptoms is based on the healthy, white male ("Medicine's Biggest Blind Spot - Women's Bodies - Dx IQ Column," n.d.). For example, the most known symptoms for heart attacks include a clutching chest pain, pain shooting down the left arm, and gasping for air. But all these symptoms are more common in men, and they are so widely popular because so many studies involving studying these symptoms were performed with white men. In reality, signs in women can be much more common: fainting, general weakness, shortness of breath, etc. ("Medicine's Biggest Blind Spot - Women's Bodies - Dx IQ Column," n.d.).

The truth is women are taken less seriously and treated less frequently for their pain (*The Pain Gap Is Even Worse for Black Women*, 2021). A major contributing factor is that women are labeled as hysterics who exaggerate their pain (*Gaslighting in Women's Health: When Doctors Dismiss Symptoms | Northwell Health*, n.d.). This leads to women being recommended for

psychotherapy to manage their pain instead of being prescribed medications. A study was performed where subjects were shown clips of male and female patients with chronic shoulder pain to quantify the patients' pain intensity and determine the course of treatment. Based on perception and non-verbal cues, the subjects underestimated the female patients' pain compared to the male patients' and determined that the male patients were more likely to benefit from pain medication than the female patients (Zhang et al., 2021).

Effects of the Lack of People of Color and Women in Current Research

Current studies do not sufficiently sample people of color and women, continually diminishing the information available about these populations due, in part, to the difficulties finding willing participants and supporting the costs of uninsured subjects. Great leaps are constantly being made in medicine, including the development of drugs for prevalent cancers, but these great leaps disproportionately ignore minority populations (Wong, n.d.). A recent study found that people of color are under-represented in clinical trials for drugs to treat cancers that disproportionately affect these populations. Ninlaro, a promising drug for multiple myeloma, a blood cancer, was recently approved by the Food and Drug Administration (FDA). Although one in five multiple myeloma patients are African American and African Americans are twice as likely as White Americans to be diagnosed with a blood cancer, only 1.8% of the participants in Ninlaro's clinical trials were of African American descent (Wong, n.d.). This is not the first drug to display such participant demographics. Minorities are often not included in clinical trials for promising drugs because of financial hurdles, logistical challenges, and the lingering distrust of the medical community due to previous unethical experimentation (Wong, n.d.).

Lack of Representation of People of Color in Pulse Oximeter Studies

As a result of the pandemic, more irregularities in medical device approval have come to light. The popularity of the pulse oximeter, a device that shines light through the fingertip to estimate the blood's oxygen saturation, has raised concerns about the racial disparity in the device's measurements (*FDA Starts Review of How Skin Pigmentation Affects Pulse Oximeter Results*, n.d.). One of the symptoms of early coronavirus strains was increased fatigue and shortness of breath, so people sought out pulse oximeters to measure respiratory status at home. The issues regarding racial disparity in pulse oximeters date back to the 1980s and 1990s when the device was first approved, but at this time no link was found between skin pigmentation and pulse oximeter results due to the insufficient research conducted before approval (*FDA Starts Review of How Skin Pigmentation Affects Pulse Oximeter Results*, n.d.).

Recently, the New England Journal of Medicine published a letter about a study that found black patients were more likely to have occult hypoxemia, which was not detected by the pulse oximeter. Studies by the FDA about this have increased the range that pulse oximeters could be displaying: a reading of 90% could reflect a blood oxygen level as low as 86% and as high as 94% (*Effects of Skin Pigmentation on Pulse Oximeter Accuracy at Low Saturation | Anesthesiology | American Society of Anesthesiologists*, n.d.). At low blood oxygen levels, the pulse oximeter tends to be more inaccurate where accuracy is an important factor determining the course of diagnosis and treatment.

These discrepancies arose because the pulse oximeter was created and calibrated with light-skinned individuals in mind. A major factor contributing to the inaccuracies of the pulse oximeter is that the absorption spectra of melanin (the pigment contributing to darker skin tones) and deoxy- and oxy-hemoglobin (hemoglobin is the protein that binds and carries oxygen around

the body) overlap (Vesoulis et al., 2022). Further testing of this theory has confirmed that most pulse oximeter models show a similarly consistent positive bias at low blood oxygen levels, meaning that at low levels of oxygen saturation, the pulse oximeter displays a higher than true level of saturation.

Lack of Representation of Women in Medical Studies

Women have also been inaccurately sampled in important studies. Women's bodies as well as conditions that primarily affect women have been studied far less in clinical trials (*The Pain Gap Is Even Worse for Black Women*, 2021). This makes finding drugs that help women or even characterizing disease progression in women so much more difficult. Beginning around the 1970s, studies began mixing male and female subjects within groups under the guise of equality. Although legislation regarding women's health and gender-based research has gathered much less funding, efforts by the National Institute of Health (NIH) have required the inclusion of women in clinical trials (Holdcroft, 2007).

Still, the lack of information and biases continue to prevail in research. Recent trials are composed of only 16% women, even if the drugs display a dramatic difference in symptoms between male and female patients (Holdcroft, 2007). One reason for this is the adverse effects of drugs to women's reproductive systems. In order to reduce this type of harm, women are constantly disregarded and not even asked to participate instead of being presented with the facts from previous research and being allowed to make the decision. Similarly, stroke is the third leading cause of death in women while it is the fifth leading cause of death in men. However, healthcare workers and the public know more about the physical representations of stroke in men rather than in women ("Medicine's Biggest Blind Spot - Women's Bodies - Dx IQ Column,"

n.d.). The purpose of research is to benefit all people, but government-induced restrictions disproportionately affect minorities, including women. The lack of information from misrepresentative studies has spread from research studies, labs, and hospitals into homes where it has cemented itself as the truth. With the advent of technology, much of this research is available through popular media articles where it becomes distilled into simple facts that do not display the complex interactions in a research article. Many individuals who do not know about the complex interactions take the information at face-value, leading to harmful misinterpretation and a lack of true understanding.

Efforts to Include Minority Groups in Research

Various government and research agencies have taken steps to mend the issue of representation. The Healthcare Research Act of 1999 requires incorporating disparities based on socioeconomic status, race, and ethnicity as well as women, children, elderly, and those with special health care needs (Bilheimer & Klein, 2010). The Healthy People 2020 (HP2020) report by the Center for Disease Control (CDC) has emphasized social, economic, and environmental determinants on health (Bilheimer & Klein, 2010). Furthermore, the passage of the Patient Protection and Affordable Care Act requires that federally conducted programs collect information on race, ethnicity, sex, primary language, etc. to facilitate reliable conclusions about minority subgroups (Han et al., 2015). The creation, implementation, and spread of these reports has increased awareness in the academic community as well as laid out specific guidelines to follow when conducting research (Nambi Ndugga & Samantha Artiga, 2021).

Small sample sizes for studies restrict the ability to measure disparities. This problem is compounded at smaller levels where studies show wide variations within subgroups. Targeted

surveys have been implemented to combat this problem (Bilheimer & Klein, 2010). The National Health Interview Survey (NHIS) has been created to oversample minority populations such as African Americans, Hispanics, and Asians. Similarly, studies such as the National Health and Nutrition Examination Survey (NHANES) and the Medical Expenditure Panel Survey (MEPS) have been used to learn more about physical examinations, hospital visits, and expenditures (Bilheimer & Klein, 2010). The data from these studies provide information on key variables which can be used to identify disparities that might not otherwise be measured.

A key part of mending existing problems is raising awareness about them in both the people affected and the people who can fix the problem. The COVID-19 pandemic has really increased awareness on these issues. The Healthy People reports released by the CDC attempts to do this by defining common terms such as “health inequality” and “disparity.” A great landmark of this report is that it highlights how disparities adversely affect groups who experience greater obstacles to health based on racial or ethnic reasons (Bilheimer & Klein, 2010). The changes in definitions as these reports are released follow the changing sentiment from the public. However, with the shift due to the pandemic, a lot of these reports have become more publicized and more accessible to the public. Although reading long reports with complicated terminology is not feasible for everyone, the pandemic has initiated the creation of easier-to-understand figures and tables to present the same data. The increased accessibility to this information helps the public realize the issues at hand and provide support for combatting the problems.

Analysis of Historical Events in Medicine Through Unintended Consequences

Although many new strides are being taken to incorporate minorities into research, the extent to which they will be effective is limited. Through the framework of unintended consequences, we can analyze how the past actions continue to create an environment of mistrust and fear. Unintended consequences result due to a lack of knowledge, errors in judgment, biases or values that other considerations, or self-defeating prophecies (Bruce Edward Tonn & Dorian Stiefel, 2018). Consequences can be grouped into three different categories: anticipated-intended consequences (AICs), anticipated-unintended consequences (AUCs), and unanticipated-unintended consequences (UUCs). For this analysis, I will be focusing on the latter two categories (Bruce Edward Tonn & Dorian Stiefel, 2018).

Even so early as after the Tuskegee Syphilis study, these consequences are present. The goal of the study was merely to learn more about the progression of the disease (Katz et al., 2008). However, by manipulating their subjects and withholding treatment, the healthcare workers lost the trust of the community. By observing this situation from a current-day perspective, it is easy to denote the loss of trust as an AUC; obviously, the healthcare workers knew this would happen if the public found out. The UUC in the situation appears when we consider the change in societal position of this minority group. In the mid-1900s, it would have been hard to envision the strides the black community has made towards equality. Even with these strides, there is a lack of trust in public institutions due to the history of malpractice and violence (Musa et al., 2009).

Beyond the scope of the black community, overall confidence in the medical system has decreased significantly from 1975 to 2015, 80% and 37%, respectively (Musa et al., 2009). The healthcare system has become continuously more profit-oriented, displaying a more impersonal

environment. Before the creation and implementation of the Patient Protection and Affordable Care Act, more than one in four Americans did not have healthcare. Healthcare was either provided through Medicare, employers, or individuals had to purchase it on their own. Before the Affordable Care Act (ACA) was implemented, insurance prices were rising far faster than incomes. The implementation of the ACA, however, allowed disproportionately affected low-income families to receive insurance and decreased the variation in coverage across the states (Han et al., 2015).

Since the spread of the ACA, insurance-based discrimination has risen (Han et al., 2015). The goals of the ACA were to increase access to healthcare and make it affordable for more families. However, no one realized the impact the ACA would have on healthcare systems. Since, similar to Medicare and Medicaid patients, those covered by the ACA are given a government-subsidized insurance plan, the profit made by healthcare systems who accept more of these patients is far less than the profit made through patients who are covered under private insurance plans. A recent study found that reports of insurance-based discrimination was approximately 6 times higher among uninsured adults and approximately 4.5 times higher in publicly insured adults than among privately insured adults (Han et al., 2015). Although the ACA did not aim for these disparities to propagate from other types of government-provided insurances, the stigma around the socioeconomic status that requires this type of insurance has prevailed. The damage of this stigma is more present in states with highly variable types of insurance coverage where areas with more government-provided insurance coverage receive fewer public health screenings and reduced access to healthcare systems.

Stigmas surrounding people of color and women have cemented themselves in many Americans, including healthcare workers. When other disparities such as insurance status,

income, age, and severity of conditions are removed, ethnic and racial minorities still receive lower quality care and suffer a worse prognosis. Many preliminary studies from the early 2000s have shown that bias, stereotyping, and clinical uncertainty may contribute to these health disparities (“Historians Take Note,” n.d.). Healthcare settings have increased the frequency of implicit and explicit bias training, but these annual or biannual trainings are not enough to remove deeply engrained beliefs.

A study released from the University of Virginia (UVA) surveyed medical students in their first three years as well as residents about common myths surrounding black and white patients in healthcare (Kelly M. Hoffman et al., 2016). A statistically significant number of students believed that black people were less sensitive to pain when compared with white people and that they age slower, have thicker skin, etc. (Kelly M. Hoffman et al., 2016). Most of these beliefs persisted from first-year medical students to residents highlighting how their education does not seem to be removing these false implicit beliefs. Medical education is geared towards teaching students so much information about the body and how to interact with patients and how to diagnose a large variety of diseases; however, it fails to teach them how to remove the stereotypes, bias, and prejudice that they have gathered throughout their lives to treat each patient equally.

Does Trust Still Prevail?

While it is true that many people still trust their primary care doctors, this level of trust does not extend to larger healthcare settings such as the emergency room (ER) (Musa et al., 2009). A random telephone digit survey of adults in the US showed that all adults trust their primary care physician much more than a physician in a larger healthcare setting, an effect that is

compounded when analyzing the results by minorities (Musa et al., 2009). These results make complete sense when considering the frequent visits that build repertoire between a patient and a doctor. When analyzing other settings like the ER, not many patients know any of the ER doctors or may have had previously negative experiences at the ER. Furthermore, studies show that people of color and women wait approximately 15 mins longer in the ER waiting room to be seen by a doctor compared to their white, male counterparts (“Medicine’s Biggest Blind Spot - Women’s Bodies - Dx IQ Column,” n.d.). This is a 33% increase in waiting time, and in the event of a serious situation, it could lead to bad results.

Conclusion

Medicine has a long history of malpractice and negligence relating to people of color and women. These groups have long been excluded from important clinical trials and studies about disease progression (“Medicine’s Biggest Blind Spot - Women’s Bodies - Dx IQ Column,” n.d.; Wong, n.d.). Efforts to include them in these studies have been plagued with unethical methods that has decreased these groups’ trust in healthcare systems. With time, distrust has decreased, especially in regards to primary care physicians (Musa et al., 2009). However, the expansion of government-aided insurance through the ACA has led to insurance-based discrimination as healthcare systems prioritize profits over equal care (Han et al., 2015). Many of these long-term side effects are hard to detect by analyzing the effects of these systems before implementation; however, through historical analysis and the framework of unintended consequences (Bruce Edward Tonn & Dorian Stiefel, 2018), we can begin to analyze these effects. Implicit and explicit bias training has been enforced by healthcare institutions to remove the biases and stigmas that often plague effective diagnosis and treatment. However, the irregularity of this

training as well as the long-standing notions that medical students enter medical school will reduce their efficacy (Kelly M. Hoffman et al., 2016). Enforcing implicit and explicit bias training from earlier ages as well as creating stricter guidelines to include people of color and women in research, especially research that disproportionately affects these groups, will begin to bridge the gap seen in healthcare. It is important to understand the history that has shaped the current environment to navigate a way forward. Studying historical events can highlight how views on many decisions change based on societal values at the time and how the public opinion on those decisions affects trust in institutional groups. Learning from these trends allows mistakes not to be repeated and effects to be studied more deeply.

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