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THE LASTING EFFECTS OF HISTORY ON AFRICAN AMERICAN ATTITUDES
AND BELIEFS TOWARDS THE AMERICAN HEALTHCARE SYSTEM

by
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A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of
the requirements of the Sally McDonnell Barksdale Honors College.

Jackson
May 2015

Approved by

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ABSTRACT

The Lasting Effects of History on African American Attitudes and Beliefs towards the American Healthcare System

The purpose of this thesis is to explore the lingering physical and psychological effects that a history of medical exploitation has had on the African American community's view of healthcare. This thesis presents historical events, statistics, and qualitative research that give insight into some prevalent feelings of mistrust in the African American community that could serve as barriers to seeking medical attention. Through exploration of African American history, this thesis delves into the issues of fear and the lack of trust in the healthcare system that some African Americans possess. Additionally, this paper not only explores the ethical failings of the past, but it also highlights the impact that history has on the health status of African Americans today.

Historical accounts of medical exploitation, statistics on the health status of African Americans from the Centers for Disease Control and Prevention, and findings from qualitative research studies are all used to explore this topic further and highlight plausible reasons that African Americans have, traditionally, not sought healthcare at the rates of other races. The numerous historical accounts from the early 19th to the late 20th centuries will first show a trend of unethical medical misconduct in regards to African Americans; then, statistical data collected from the Centers for Disease Control and Prevention and other public health entities will paint a picture of the current health status of African Americans; lastly, the thesis analyzes quantitative and qualitative data to summarize the lingering psychological effects of past medical exploitation and advancements that are being made to improve the health status of African Americans.

Together, all of the research and information will provide understanding into some of the reasons why African Americans are slow to seek healthcare, resulting in an overall poor health status.

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THE LASTING EFFECTS OF HISTORY ON AFRICAN AMERICAN ATTITUDES AND BELIEFS TOWARDS THE AMERICAN HEALTHCARE SYSTEM

CHAPTER 1

THE HISTORY OF MEDICAL EXPLOITATION OF AFRICAN AMERICANS

African American history is riddled with the recurring themes of maltreatment and exploitation. From the capture and enslavement of Africans until after the time of emancipation, there have been numerous historical accounts of enslaved African Americans being used for agricultural, economical, and many times, medical advancement. Over the course of history there have been many instances of medical exploitation of African Americans, and many of the medical breakthroughs of the past and much of the medical knowledge that we venerate today has been made possible through the debasement and desecration of African Americans (Washington, 2006).

From their introduction to this country, African Americans have had a long history of abuse, and studies have concluded the memories of experimentation that many endured for the sake of medical advancement still remain in the minds of some African Americans today (Jacobs et al., 2006). Some of the most notable historical instances of medical exploitation that will be discussed in this chapter are the writings of Dr. Samuel A. Cartwright, a doctor whose experiments and publications helped fuel inaccurate beliefs about the physical make up of blacks; the famed surgical techniques of Dr. J. Marion Sims, the “Father of Gynecology,” that were perfected on enslaved women; the physical exploitation of Henrietta Lacks for monetary gain; the unethical experiment that

was the Tuskegee Syphilis Study; and the forced sterilization of black women in the South in 1970s and 80s.

Samuel A. Cartwright

There have been many accounts of medical exploitation of African Americans from the early 19th century when slavery was abundant. Much of the maltreatment and experimentation of African Americans stemmed from a misunderstanding of this new race of people that had been captured and brought to America. Many of the racist beliefs that were widely accepted during that time were due to immature scientific theories, misguided religious beliefs, and Eurocentric views that deemed other races inferior. According to Harriet A. Washington, a researcher at the National Center for Bioethics at Tuskegee University and author of “Medical Apartheid,” a common opinion of the era was that “blacks were physically inferior and were liars, malingerers, hypersexual...indolent... and most often compared to beasts” (Washington, 2006, p. 35). To some, the new found Africans were viewed as an “entirely different species of men with...different characteristics...” (Washington, 2006, p. 34). To others, they were seen as being of the same species of whites, but made inferior by “environmental and social pressures” (Washington, 2006, p. 34). A prevailing scientific opinion was that African Americans had devolved from the evolutionary status of whites, which accounted for their inferiority (Washington, 2006). These theories of black inferiority were prevalent and pervasive ones of the time, and these perspectives aided in the mass opinion that African Americans were sub-human, inferior beings- a belief that would facilitate the chronic mistreatment of African Americans for upwards of a century.

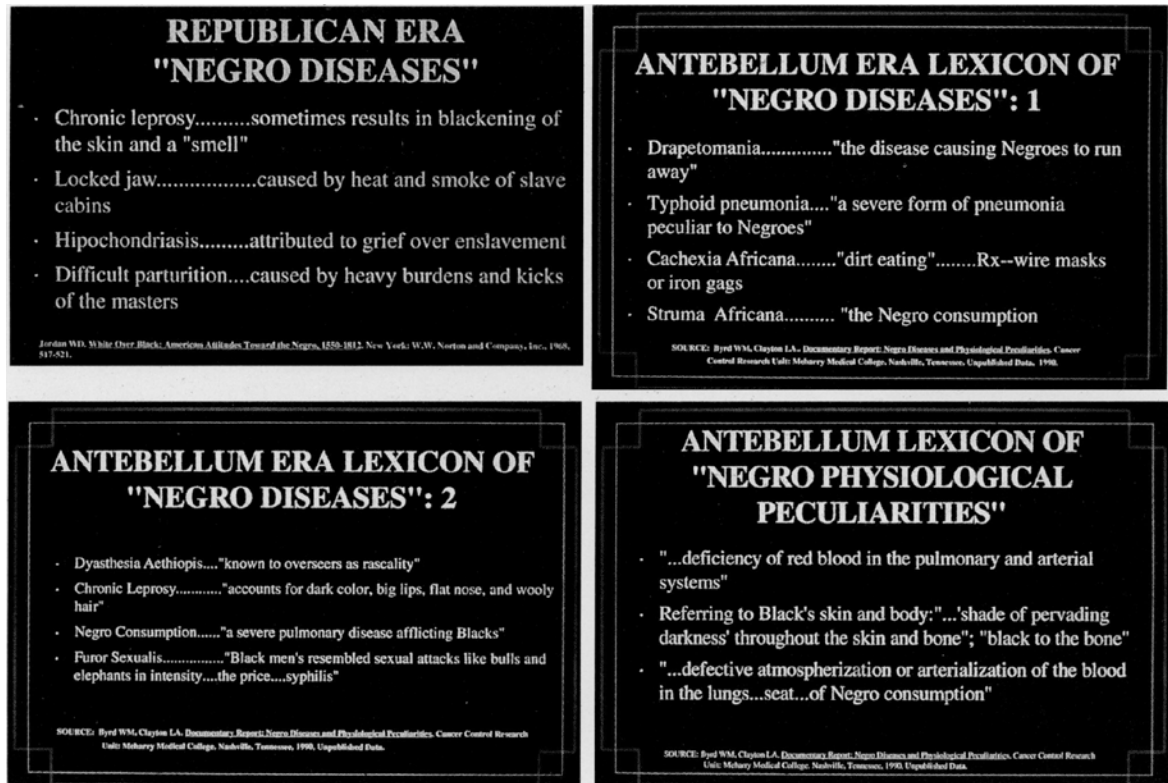
In 1850, Dr. Samuel A. Cartwright became the chair of a committee of the Medical Association of Louisiana that was to research the physiology and health of African Americans; in the same year, he published a paper entitled “The Diseases and Physical Peculiarities of the Negro Race.” In this paper, he named physical and mental inferiorities he claimed to have observed in African Americans. Throughout his paper, Cartwright supported his findings with misguided Biblical references and unsound scientific theories (Washington, 2006). In Cartwright’s medical opinion, African Americans were so different from whites that “the same medical treatment which would benefit or cure a white man, would often injure or kill a negro, because of the differences in the organic or physical character imprinted by the hand of nature on the two races” (Cartwright, 1850). In his writings, he denounces researchers who sought to prove the brains of whites and blacks were the same. Instead, he claims to be true the notion the brains of black people were, indeed, smaller than those of white people, causing them to be inferior in intellect. Cartwright also supported the findings of others who compared the physical features of black people to orangutans, and supported claims that the density of the skulls of black people was so similar to the skulls of ancient Ethiopians, that it meant that black people had not evolved over time as the white man had.

In his paper, Cartwright writes of his discovery of certain diseases that only befell black people. Most of the “black” diseases that Cartwright “discovered” were similar in that their “principal symptoms seemed to be a lack of enthusiasm for slavery” (Washington, 2006, p. 36). The first disease Cartwright writes about is *drapetomania*, “the disease causing negroes to run away” (Cartwright, 1850). This “disease of the mind,” as Cartwright called it, was not an incurable disease, but it could be remedied by

maintaining the slave in the “position of submission” that “he was intended to occupy” (Cartwright, 1850). Cartwright described the symptoms of this “disease” as being “sulky and dissatisfied,” and he offers advice on how to remedy this common problem (Cartwright, 1850). Cartwright coined the term, *dysaesthesia aethiopica*, to describe what he thought was a tendency of black slaves to be lazy, prone to sleepiness, and destructive of property. He attributed skin lesions, findings that certainly were a manifestation of an unrelated health problem, as a symptom of the “disease.” Cartwright’s treatment for *dysaesthesia aethiopica* was to “put the patient to some hard kind of work in the open air and sunshine...” (Washington, 2006, p. 36). After the publication of Cartwright’s theories, other physicians soon added their own discoveries of mysterious diseases that only plagued African Americans. *Cachexia Africana*, for example, was a term used to describe the “supposed propensity [of African Americans] for eating...clay, chalk, and dirt” (Washington, 2006, p. 36). It is now known that this condition, correctly diagnosed as “pica,” derives from a nutritional deficiency, likely caused by the less than adequate meals the slaves were provided.

Cartwright’s writings prompted more people in the medical community to seek to learn more about the alleged vast physical differences of African Americans. Cartwright’s publications sparked a landslide of theories on the inferiority of blacks and their immense physical peculiarities that perpetuated racist stereotypes that quickly pervaded the medical profession.

Figure 1-1: Lexicon “black diseases” utilized by health professionals until the 20th century



(Byrd et al, 2001)

Slavery was an era which afforded physicians and the medical community an opportune chance for medical advancement; slaves were plenty, and because the slaves were not seen as humans that were entitled to legal rights, but were instead considered property, the owners of the slaves had the full authority to do what they wished with them. Many times slaves were sold or traded to be used explicitly for the purpose of medical experimentation if they had become too sick or too old to work or be of any use to their owners (Washington, 2006). In addition to the growing number of new pseudoscientific diagnoses that were appearing at that time, several other racist beliefs, such as the beliefs that African Americans did not feel pain like whites, African

Americans harbored different diseases, and diseases were expressed differently in African Americans, perpetuated the practice of medical experimentation.

As one example of plenty instances of slave experimentation, former slave John Brown retells accounts of experiments that were performed on him by a white physician in his 1847 memoir, *Slave Life in Georgia* (Washington, 2006). As a token of appreciation for curing him of an ailment, Brown's owner gave him to a local physician. The doctor's plan was not to use Brown as a field or a house slave, but his intent was to use Brown as a test subject. One of the doctor's goals was to find a treatment for heat stroke. In Brown's memoir, he tells of times when the doctor would put him down into a covered pit with a fire burning to induce the effects of a heat stroke, only to help him to recover and start the experiment again. Brown also told of times when the doctor would cause him to bleed or to blister "to ascertain how deep my black skin went" (Brown, 1847). Brown's account tells of many different experiences such as these that he endured before his escape to England in 1847 (Washington, 2006). Brown was one of many slaves that served as test subjects for physicians without much regard for their welfare.

James Marion Sims

Dr. James Marion Sims is an important figure in the history of the medical exploitation of African Americans. Today he is hailed as the founding father of gynecology and is revered for his groundbreaking treatment of vesicovaginal fistulas, performing the first gallbladder surgery, and making strides in the use of aseptic technique during surgeries. However, many of his medical successes and his renowned fame derived from cruel and inhumane origins. During the process of making his famous

medical breakthroughs, Sims conducted numerous experimental surgeries on enslaved women, often without anesthesia or consent (Washington, 2006).

J. Marion Sims was born in 1813 into meager beginnings in South Carolina. In his autobiography, *The Story of My Life*, he shared that even though his father was without an education, he encouraged Sims to seek education. Despite his being a less than extraordinary student, Sims went on to attend South Carolina Medical College and then Jefferson Medical College in Philadelphia, Pennsylvania (Sims, 1884). After finishing only a year and a half of instruction that was typical for that time, Sims moved to Alabama to practice medicine.

Soon after his arrival to Alabama, Sims tells of his interactions with slave children who suffered from tetany, a condition manifesting itself as convulsions and muscle spasms. Tetany is the result of a calcium, magnesium, and vitamin D deficiency, which was a common ailment due to the malnutrition of the slaves (Mosby's, 2009). Sims concluded tetany derived from unnatural overlapping of the skull bones of African Americans during birth. A prevailing belief of that time was that the skulls of blacks were unusually small, which resulted in unintelligence and child-like behavior (Washington, 2006). To remedy the problem, Sims would pry the skull bones of the children apart in an attempt to open the skull to give the brain more room to grow and develop, a practice that resulted in the deaths of numerous slave children with the condition (Washington, 2006).

As Sims' time in Alabama progressed, he was presented a problem that would later become his claim to fame. He encountered a young slave girl who had been having a long and difficult labor. To deliver her child, Sims performed a forceps delivery.

Although the child was successfully delivered, the tedious labor left the young woman with a vesicovaginal fistula, an abnormal passageway that connects the bladder and the vagina (Mosby's, 2009). Vesicovaginal fistulas were occasional occurrences seen in women who experienced difficult childbirths. These fistulas caused pain, incontinence, and emotional scarring in the women that suffered from them (Washington, 2006). Once Sims saw the need for a cure of such a debilitating ailment, he sought to find it. Since it was unlikely that white women would subject themselves to multiple painful experimental surgeries, Sims looked to test subjects that did not have to be convinced, compensated, or coaxed to participate. He chose eleven slaves with vesicovaginal fistulas to be his subjects for his experimental surgeries (Washington, 2006). Over the course of four years, Sims practiced and perfected his method of repairing vesicovaginal fistulas using these slave women. Occasionally, the fistulas would reopen or would be reopened only to be once again closed, without the use of anesthesia (Washington, 2006). Sims cited the common belief of black's enhanced tolerance of pain to be the reason anesthesia was not used, as well as his conclusion that the procedure was not painful enough to "justify the trouble and risk" of using ether as anesthesia (Washington, 2006, p. 64). However, after the procedure was perfected enough to repair the vesicovaginal fistulas of white women, Sims, then, employed the use of anesthetic agents during his surgeries (Washington, 2006).

Sims' technique of correcting vesicovaginal fistulas has been a groundbreaking finding in the field of gynecology. His work has helped to lay the foundation for modern gynecology, and has earned Sims a permanent place in history. Unfortunately, Sims'

famous breakthrough came at the cost of human lives, and has been a building block in the formation of the mistrust of medicine by African Americans in the present.

Henrietta Lacks

One of the most notorious instances of medical exploitation for profit in the early 20th century is the case of Henrietta Lacks. Lacks was a black woman whose life and death made, and still continues to make, a great impact on science and medicine. Her story is one which highlights the issues of medical bioethics, patient's rights, and exploitation of vulnerable populations.

Henrietta Lacks was born into a poor black family in Roanoke, Virginia in 1920. After the death of her mother, she and her nine siblings were divided among relatives; and she was placed with her maternal grandfather in Clover, Virginia. Lacks attended school until the sixth grade, after which she stopped attending to work in the tobacco fields along with her family. Henrietta bore her first child at fourteen and would later have four more. In 1951, Lacks sought medical help at Johns Hopkins Hospital for unusual vaginal bleeding. Johns Hopkins was one of the first hospitals in Baltimore, Maryland to provide medical services to African Americans, but the hospital remained segregated, however (Skloot, 2010). The public ward was a place designated for "colored" people to come to seek healthcare for free of charge. However, doctors would often use "patients from the public wards for research, usually without their knowledge...as a form of payment" (Skloot, 2010, p. 30). There, Lacks underwent numerous tests which found her to have a cancerous tumor on her cervix. During a return visit to Hopkins, Lacks received surgery to implant the radioactive metal, radium, into

her cervix in an attempt to destroy the cancerous cells. When it was first discovered in the late 1800s, radium was considered a cure-all and in the early 1900s it was commonly used to treat cervical cancer. It was later discovered that that while the radioactive properties of radium destroyed malignant cells, it also destroyed healthy tissue and caused healthy cells to mutate into cancerous cells (Skloot, 2010).

While Lacks was undergoing this procedure, a sample of her cervical tissue was collected, sent to pathology, and labeled “HeLa,” to differentiate her tissue samples from the others in the lab. Lacks then left the hospital without any knowledge of the sample taken. After Lacks was sent home, it was discovered that the cancerous cells biopsied from her tumor were growing expeditiously. While the non-cancerous cells taken from her had shown little growth and soon died, the malignant cells were doubling by the day. Soon after, word spread about the possibility of the discovery of the first immortal human cell line; and scientists scrambled to obtain samples of their own.

Henrietta Lacks was told she was to return every two weeks for more radium treatments, but she was not provided other important details of her treatment, as evidenced by documentation in her medical record. After weeks of radiation treatments, it was documented Lacks asked her physician when she could start attempting to become pregnant again. One of her doctors recorded the encounter: “Told she could not have any more children. Says if she had been told so before she would not have gone through with treatment” (Skloot, 2010, p. 48). Situations of being under-informed were common occurrences, as the African American population that sought healthcare at the public wards of Johns Hopkins at that time was comprised of mostly the uneducated poor, and the mindset of the physicians treating them was that they knew what was best. The

patients were not made active members in their own care. But in a time when hospitals frequently denied care to African Americans, black patients were hesitant to ask questions, but quietly accepted the care that was given (Skloot, 2010).

Three weeks after the collection of the “HeLa” cells, the biologist in charge of the pathology went public with the groundbreaking finding. He exclaimed the cells showed incredible promise for a future cure of cancer, because these cells provided the unlimited access to malignant cells scientists needed to experiment in a way that would not be ethical or feasible in a living human (Skloot, 2010). The cells gave researchers innumerable chances to practice and experiment. So, the cells were widely publicized and distributed, but without any mention or recognition of the woman from which they had come (Skloot, 2010).

As time progressed, Lacks would report to her scheduled appointments complaining of increasing discomfort. Each visit would result in the same documentation and recommendation from her doctors: “No evidence of reoccurrence. Return in one month” (Skloot, 2010, p. 64). After two and a half months of reporting increasing amounts of pain, Lacks was examined and X-rayed only to find that numerous tumors had grown on Lacks’ kidneys, bladder, and uterus, all of which the doctors deemed inoperable (Skloot, 2010, p. 64). Lacks was admitted into Johns Hopkins for palliative care. Rebecca Skloot, a writer who researched Lacks’ life and wrote Lacks’ biography, *The Immortal Life of Henrietta Lacks*, stated that in her investigations, she found no evidence that the biologist that was the director of the pathology lab that housed and promoted the use of “HeLa” cells ever met or spoke to Lacks about the use of her now

famous cells (Skloot, 2010). After weeks of suffering, Henrietta Lacks died on October 4, 1951.

After Henrietta Lacks' death, her family was made aware that some of their mother's cells were still living in labs and were being used for medical research. But it was not until 1975 when the family of Henrietta Lacks learned the true importance of the cells and they were being sold for profit. An article was brought to the family's attention stating the cells were being sold to research institutions all over the world for roughly \$25 per vial (Skloot, 2010). The family then came to the realization their mother's cells, obtained without her consent, were being sold for millions of dollars of profit. Even more so, researchers had started calling the unknown woman behind the cells "Helen Lane" (Skloot, 2010). The family of Henrietta Lacks felt as if a part of their mother had been stolen, exploited, and violated, and that the person behind the "HeLa" cells had been pushed to the wayside and forgotten.

It was not until the publication of the biography of Henrietta Lacks was her story revealed to the modern public. *The Immortal Life of Henrietta Lacks* uncovered the unfairness that the family of Henrietta Lacks experienced, and the fight to gain rights to the famous cells that continue to be used in medical experimentation today. Full disclosure is a tenet that should be an essential part of healthcare. Situations without it, such as the situation with the Lacks family, breeds suspicion and mistrust that may be hard to overcome.

The Tuskegee Syphilis Study

The Tuskegee Syphilis Study is notably one of the most well-known examples of medical ethical misconduct in the United States. Over the course of a forty year period, hundreds of African American men had been diagnosed with syphilis were denied treatment so the effects of the disease on their bodies could be observed. Not until 1972 did the United States government acknowledge the existence of the study and attempt to make amends. Because the appalling details of the study have been so well publicized, the study has had a long-lasting effect on the African American community's views of the trustworthiness of the healthcare system (Jones, 1993).

The Tuskegee Syphilis Study was an experiment conducted by the United States Public Health Service (USPHS) in 1932 in Macon County, Alabama (Brandt, 2001). The purpose of the study was to evaluate the effects of untreated syphilis in African American males. The study included 400 men who were infected with the disease, as well as 200 men who were not infected that served as the control group. The participants were not made aware of their infection with syphilis, but instead, they were told that they suffered from "bad blood" (Brandt, 2001).

Syphilis is a sexually transmitted disease, first discovered in the late 15th century. It is caused by a spirochete bacterium called *treponema pallidum* and is primarily transmitted by sexual contact, but also can be transferred through pregnancy from a mother to her fetus. Syphilis is a curable disease, and when it is uncomplicated, it is treated by a single dose of antibiotics. Uncomplicated syphilis is treated with penicillin G, or by doxycycline. If the disease progresses to the latent or neurosyphilis stage, the

treatment requires large doses of penicillin given intravenously for a minimum of 10 days (Jones, 1993). The infection, if left untreated, can cause long-term physical and mental complications. The symptoms are divided into primary, secondary, and latent stages. The primary stage of syphilis is characterized by symptomatic lesions, or chancre sores, that are located at the disease's point of injury into the body. According to the CDC, the lesions are firm round, painless, and frequently go unnoticed. The duration of the lesions are from three to six weeks, and heal regardless of whether treatment is obtained. The secondary stage of the disease is characterized by rashes on mucous membranes that appear shortly after the lesions of the primary stage have healed. Also during the secondary stage of syphilis, sufferers may experience fever, a sore throat, swollen lymph nodes, weight loss and fatigue ("Syphilis," 2014). If the disease continues without treatment, it will progress to the latent stage. The latent and late stages of syphilis start after the symptoms of the primary and secondary stages have subsided. At this point in the disease process, syphilis can remain in the body for years without exhibiting more symptoms. The symptoms of late stage syphilis include decreased muscle coordination, muscle paralysis, numbness of limbs, blindness, dementia and neurosyphilis, the spread of the infection to the brain (Jones, 2001). Syphilis that has been dormant over the course of decades causes damage to internal organs that ultimately can result in death ("Syphilis," 2014). Even though the effects of the disease were known to the researchers, they continued with their quest to observe the effects of latent syphilis on the body.

The Tuskegee syphilis study started from a previous study, the Rosenwald Study, conducted by the USPHS in which the experimenters set out to investigate the prevalence of syphilis infections in African Americans in the rural South. The original purpose of the

study was to evaluate the possibility of mass treatment for those infected (Brandt, 2001). The researchers involved with the study discovered Macon County, Alabama, and found that the county had the highest rates of syphilis out of the six counties that were being studied. The results of the study concluded that mass treatment of the infected was, indeed, possible. However, due to the economic downturn that was the Great Depression, funding was not extended to provide treatment to the participants of the study, and the Rosenwald Study ended (Brandt, 2001). Three years after the study was concluded, it was revisited by the director of the USPHS Venereal Disease Division, Dr. Taliaferro Clark. He rationalized that since there were people in the Macon County community who had been living with syphilis that would have gone the entirety of their lives with the disease without treatment, the community would be a suitable population for observation (Brandt, 2001).

September 1932 was the beginning of the Tuskegee syphilis study. Researchers traveled to Macon County to gather the men that were infected with latent syphilis to serve as participants. The criteria for selection were African American men that were between the ages of 25 and 60 that were infected with syphilis. Many of the participants selected were a “poverty stricken population of sharecroppers and tenant farmers” who were persuaded to participate with the promise of being cured (Brandt, 2001, p. 21).

From the study’s inception, the researchers betrayed the trust of the participants. After being tested for syphilis, the participants were not given details about their health status. Instead, they were merely informed that they had “bad blood” and were promised continued treatment with continued participation in the study. Throughout the study, the men were told they were being given the antidote for their illness, but in reality, they

were being given mercurial ointment and insufficient dosages of neoarsphenamine, the drug of choice to treat syphilis at the time, in an attempt to “preserve the subjects’ interest” (Brandt, 2001, p. 22). Throughout the duration of the study, the men were misled and blatantly lied to in an attempt to encourage continued participation. The men were not being compensated monetarily for their participation; their willingness to participate stemmed from a willingness to be treated for their ailment, and a trust in the medical professionals that had promised to cure them. Another way that the researchers persuaded the men to continue participation over the years was the promise of funding for burial upon a participant’s death. By ten years into the study, “twice as large a proportion of the syphilitic individuals as of the control group [had] died...” and in such a poverty-stricken community, assurance of a proper burial took away the worry of what a financial burden the men’s deaths would be to their families (Brandt, 2001, p.23). From the autopsies done on the men in the test group that had died, over thirty percent of the test group were found to have died from “advanced syphilitic lesions of either the cardiovascular or central nervous system” by 1955 (Brandt, 2001, p. 25).

Further observation of the surviving participants showed that many had complications that would most likely result in death from syphilis (Brandt, 2001). Even with these findings, the researchers did not provide the cure that they had repeatedly promised to the participants. More so, over the four decades of the study, the USPHS actively sought to prevent the administration of a cure to the men from outside sources (Brandt, 2001). In the early 1940s, the USPHS contacted a group of local doctors and informed them of a list of men that were not to be treated if they sought care (Brandt, 2001). Instead, the doctors were instructed to redirect the men to the USPHS. The

Alabama Health Department was also informed that they should not treat the participants when they brought a mobile clinic into Tuskegee, Alabama. And in 1941 when the army drafted 256 of the men and required that they be treated for syphilis, the USPHS informed the army of the names of the men that they wished to be excluded from treatment (Brandt, 2001).

The Tuskegee Syphilis Study proceeded for forty years until details of the experiment were made public in July 1972 (Brandt, 2001). In a report issued by a panel given the responsibility to respond to the newly released details of the experiment and decide if the experiment should be ended, it was found that the researchers were unethical in their dealings with the participants (Brandt, 2001). Denying available treatments, neglecting to obtain fully informed consent, and deceiving the participants were three major violations of the participants' rights. After all of the details about the study were revealed, the USPHS had no other choice than to terminate the study.

Deception was a common trend throughout the duration of the Tuskegee Syphilis Study. In order to obtain participation and ensure continued participation, the USPHS had to falsify the intent of the study, lie to the participants about findings, and promise the men a cure that the conductors of the study knew would never be provided. The men participating in the study, as well as their families, relied on the conductors of the study to give them the treatment they sought and desperately needed. Instead, they were given insufficient treatments, placebos, and were repeatedly misled. By participating in the study, the men were giving their consent for treatment, not for the experiment that they were then made a part of. When the details of the study were publicized in 1972, the African American community, as well as the rest of the country, was shocked at what had

taken place. Once again, a community had seen the trust that they had placed in the healthcare system be betrayed.

Eugenics and Surreptitious Sterilizations

The rise of the birth control movement was seen as a time of liberation for women. For the first time women were in control of their own bodies. They were able to control the number of children they bore, or if they had any children at all. To women who desired this freedom, the birth control pill and permanent methods of contraception provided a legal and convenient method to control reproduction. But in the African American community, such a movement was perceived as an attack. In 1939 in New York City, Planned Parenthood founder and birth control pioneer, Margret Sanger spearheaded the Negro Project, an attempt to provide birth control to poor African Americans (Washington, 2006). Sanger was a proponent of eugenics, which attempted to rid society of those who were thought to possess less than favorable characteristics. With the start of the Negro Project, many believed this was an attempt to eradicate the African American population. Planned parenthoods and similar clinics that dispersed and encouraged contraceptive use started to appear in African American neighborhoods as a result of the Negro Project, where birth control methods were made available for little or no cost. In the eyes of the African American community, this was an attempt at African American genocide. According to a survey conducted in the late 1960s, “twenty-eight percent of the blacks surveyed...agreed that encouraging blacks to use birth control is comparable to trying to eliminate this group from society” (Washington, 2006).

In the South, eugenics was being practiced by a more “invasive and permanent” approach. In 1935, twenty-seven states had laws that would allow for the sterilization of the “mentally unfit, those on welfare, or those with genetic defects,” with African Americans comprising a disproportionate percentage of the total (Washington, 2006). Harriet Washington reports in her book, *Medical Apartheid*, that “when the North Carolina Eugenic Commission sterilized 8,000 mentally retarded persons throughout the 1930s, 5,000 were black. By 1983, when blacks constituted only 12 percent of the population, 43 percent of the women sterilized in federally funded family planning programs were African Americans” (Washington, 2006). Reasons for the disproportionate numbers of black women being sterilized stemmed from increased pressures from physicians to undergo hysterectomies. After the parents of two twelve and fourteen year old girls discovered that their daughters had been sterilized without their knowledge in 1977, the Southern Poverty Law Center (SPLC) filed a lawsuit that challenged federally funded sterilizations. In their research of the matter, the SPLC uncovered that 100,000 to 150,000 poor women, half of whom were African American, had been “sterilized annually under federally funded programs” (“*Relf v. Weinberger*,” 1977). Many women were told by physicians that they would lose their welfare benefits if they did not consent to the procedure. Others were told that they were undergoing appendectomies, gallbladder removals, or routine Cesarean sections when they were really undergoing surreptitious hysterectomies, procedures that were nicknamed “Mississippi appendectomies” (Washington, 2006). By 1980, the National Center for Health Statistics reported “41% of black women who used contraception were sterilized, compared with only 27% of white women” (Washington, 2006).

Years of deception and coercion easily sets an unfavorable precedent with relations between African Americans and their healthcare providers. Repeatedly, African Americans have experienced betrayal by those who have claimed would help them. These repeated betrayals have left many with lost lives and irreparable emotional and physical scars. Repeated exploitation of African Americans has left the stain of distrust on the minds of many, and has had a profound effect on the trends that are seen with African Americans and healthcare in the present.

CHAPTER II

INSTITUTIONAL BARRIERS TO OBTAINING HEALTHCARE

In the earliest years of black inhabitation of the United States, quality healthcare for African Americans was inaccessible. Slaves faced numerous health problems stemming from poor nutrition, poor living conditions, and grueling labor demands. When slaves became ill, they were rarely seen by trained medical professionals, but were many times left to die or to be tended to by homemade remedies. Poor living conditions and lack of proper sanitation made slave quarters breeding grounds for disease. Poor nutrition made slaves more susceptible to acquiring illnesses, diseases, and congenital defects. Paired with poor nutrition, laborious and perilous working conditions put slaves at higher risk of injury and disease susceptibility. It would be years before some semblance of the healthcare system that is in place today would appear, but even in its infancy, the healthcare system was not welcoming to African Americans and did not offer the level of care that was needed.

Even after slavery formally ended in 1863 with the signing of the Emancipation Proclamation, the struggle of the newly freed African American to obtain quality healthcare did not end. Racism was just as pervasive and crippling, and the pseudoscience that deemed African Americans as intellectually and biologically inferior was still regarded as fact and continued to influence the way African Americans were viewed and treated in medical settings. African Americans were either unable to pay for the healthcare that they needed, or outright denied because of their race.

In the late 19th century, the United States government made an attempt to integrate African Americans into society and provide them more freedoms with the passing of the 13th, 14th, and 15th amendments. However with the enactment of Jim Crow laws by the states at the end of the Reconstruction Era came even more challenges for African Americans. “Separate but equal” became law to keep African Americans on the outskirts of society, and the same was true for the healthcare system. The inequality of these laws prevented African Americans from accessing quality healthcare that was equal to the healthcare that was available to white Americans. In many instances, care given to black patients was at the discretion of the healthcare provider. One such Jim Crow law enacted in Alabama in 1915 stated, “No person or corporation shall require any white female nurse to nurse in wards or rooms in hospitals, either public or private, in which Negro men are placed” (“United States National Park Service,” 2015). This law helped to ensure that African Americans would remain oppressed by the prevailing racist sentiments of the time and affected their access to healthcare. Even life-saving resources that were available to white Americans were not equally available to African Americans. During World War II, the American Red Cross announced a nationwide blood drive to collect blood that would be needed for the soldiers, some of whom were black. However, when African Americans showed up to donate blood, they were turned away, and the American Red Cross put a ban (that was later lifted) on blood donated from African Americans (Zimmerman, 2012). Blood, itself, that was collected in the blood banks was segregated. White people could never receive blood from black people, and black people could receive blood from white people only in emergencies (Zimmerman, 2012). Because

of laws in place to segregate, the quality of the healthcare that was given to African Americans was frequently inadequate.

Because of the extreme poverty of slavery that African Americans were only recently removed from after emancipation, physical access to healthcare was often difficult. The white-run hospitals and healthcare centers that were available were not readily being built in African American communities. Hospitals were being built in white communities with easy accessibility for white Americans, but very few were located in predominantly black communities. For African Americans that lived away from cities and had limited means of transportation, this meant that getting to a hospital for healthcare was difficult, and in some cases, not possible. If and when African Americans were able to get to a hospital for medical care, they often had to endure long waits while white physicians had the ability to treat white patients first, if they so chose.

Another barrier that African Americans faced was the sparse number of black physicians that were available. Since it was up to the discretion of white physicians to treat black patients, treatment by white physicians was unreliable. In his book, *The Souls of Black Folk*, the renowned Dr. W.E.B. Du Bois recounts the death of his young son. His child was sick with diphtheria and rapidly fading. Du Bois recalled an attempt to save his son's life, he pleaded the help of a white doctor, to no avail (Du Bois, 1903). Du Bois' biographer stated, "Du Bois sought out one of the few African American doctors in the city, but was unsuccessful," and soon after, his son died a death that may have been prevented had Du Bois been able to obtain the medical attention his son desperately needed (Lewis, 1993). With the founding of the Meharry Medical College, the first African American medical school and Howard University College of Medicine, African

American physicians were being produced, but there were not enough to meet the vast demand for medical care from the African American community. At the time fewer than four percent of the United States' physicians were black ("Race and the AMA," n.d.). And although African American physicians were bona fide professionals in their field, they were many times denied employment and privileges in white hospitals, as well as denied membership with the American Medical Association until 1968 ("Race and the AMA," n.d.). With the challenge of obtaining healthcare that faced black people in post slavery society, many turned to solving their ailments on their own.

The Jim Crow laws of segregation and the racial and medical oppression that accompanied them prevailed into the mid-1960s when the laws were formally abolished with the enactment of the Civil Rights Act of 1964 and the Voting Rights Act of 1965. With the inability of hospitals to continue to operate in a legally segregated fashion, the few African American communities that did have access to local hospitals and healthcare saw their only means of healthcare vanish and relocate to more "favorable" areas. The trend of hospitals closing, relocating, or privatizing after the abolition of Jim Crow laws was an attempt to marginalize African Americans and became yet another barrier for African Americans to obtain healthcare (Randall, 1996). In a study by Alan Sanger that spanned the years of 1937 to 1980, it was found that the "likelihood of a hospital's closing was directly related to the percentage of African-Americans in the population" (Randall, 1996). The loss of geographically accessible services further resulted in African Americans' inability to obtain medical access. Lack of accessibility then resulted in African Americans waiting longer than they would to treat a physical problem. Often, when African Americans finally did get medical attention, they were farther along in their

disease processes, resulting in deaths from what could have been preventable or treatable ailments.

CHAPTER III

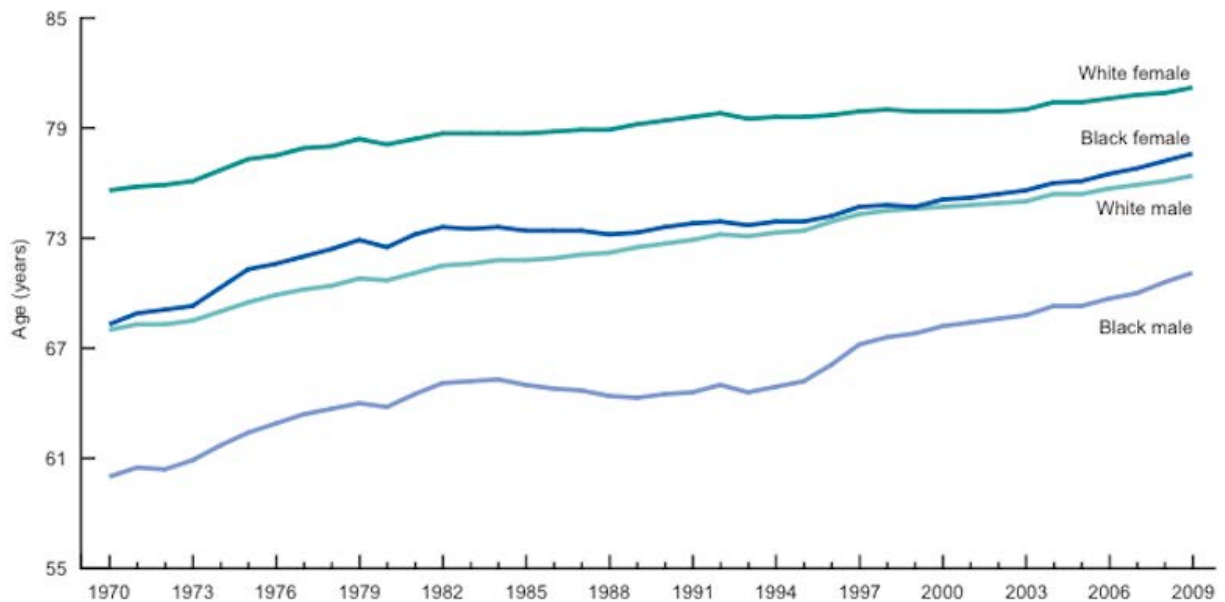
THE CURRENT HEALTH STATUS OF AFRICAN AMERICANS

When examining the statistics of reported acute medical problems of African Americans in comparison to white Americans, it would appear that African Americans have a better health status (Randall, 1993). According to the National Center for Health Statistics, “for the age group under eighteen, 36.3% fewer African-Americans than European-Americans reported acute health conditions; for the 18-44 age group, 15.9% fewer African Americans than European Americans reported acute conditions; and, for ages 45 and above, 10.1% reported fewer conditions” (Randall, 1993). However, when one examines the statistics with the same criteria, but for chronic conditions, the findings show a different picture. African Americans have a higher mortality rate than white Americans, and they report more disability from chronic diseases than do white Americans (Randall, 1993). Additionally, the National Center for Health Statistics reports, “for the under-18 age group, 20% more African Americans than European Americans reported limitations in activity because of chronic disease; for the 18-44 age group, 22.5% more African Americans than European Americans reported limitations; in the 45-65 age group, 34.8% more African Americans than European Americans reported limitations; and in the 65-69 age group, 31.6% more African Americans reported limitations than European Americans. Finally, in the seventy-and-over age group, 23.8% more African Americans than European Americans reported limitations” (Randall, 1993). African Americans on average wait longer to seek care for their conditions than other

ethnic groups, notably white Americans, which results in more complex problems and disability.

According to HealthyPeople 2020, “life expectancy is a summary mortality measure...used to describe the overall health status of a population” (“General Health Status,” 2013). Seemingly, the longer the life expectancy of a certain group, the better the health status. African Americans have the lowest life expectancy of any ethnic group in the United States. In 2009, the life expectancy of African Americans was at a four year all time low, with the average life expectancy of black men and women being 74.5 years, compared to the national average of 78 years. The 2009 life expectancy of blacks was roughly the same as the life expectancy for whites in 1980, 29 years earlier (“Life Expectancy,” 2011). White women had the highest life expectancy with an average of 81.2 years, followed by black women with an average of 77.6 years, a 3.6 year gap; white men followed with a life expectancy of 76.4 years; and, black men trailed with a life expectancy of 71.4 years, a 6.6 year gap from the national average (“Life Expectancy,” 2011).

Figure 3-1. Life Expectancy at birth by sex and race



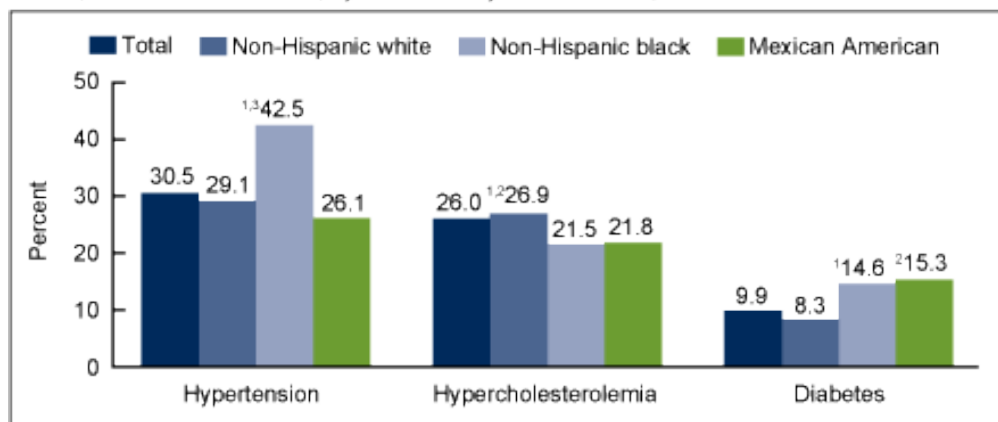
CDC/NCHS, National Vital Statistics System

Based upon the Healthy People 2020’s definition of health as interpreted by life expectancy, African Americans have a significantly lower health status than white Americans. Studies and statistics have gathered the most common causes of death for African Americans. According to the Centers for Disease Control and Prevention, in 2010, the top ten causes of death for African Americans were heart disease, cancer, stroke, diabetes, unintentional injuries, kidney diseases, chronic lower respiratory disease, homicide, septicemia, and Alzheimer’s disease, respectively. Out of the top ten causes of death, four are conditions that could be prevented or managed with early intervention and/or health education.

The top cause of death for African Americans is heart disease. According to the CDC, “African Americans in 2009 had the largest death rates from heart disease...compared with other racial and ethnic populations” (“Heart Disease

Prevention,” 2013). Heart disease, or cardiovascular disease, is a term that describes a condition that refers to the blockage of arteries in the heart. Plaque, the substance that builds up that blocks coronary arteries, is made of cholesterol deposits that causes the arteries to narrow over time in a process called atherosclerosis (“Heart Disease Prevention,” 2013). Heart disease is a serious condition that claims many lives every year; however, it is preventable through maintaining a healthy diet, maintaining a healthy weight, exercising regularly, and limiting smoking and alcohol intake (“Heart Disease Prevention”, 2013). But in many instances, African Americans do not seek medical attention until there is an overwhelming problem.

Figure 3-2. Prevalence of hypertension, hypercholesterolemia, and diabetes in adults, by race/ethnicity. United States 1999-2006



<http://www.cdc.gov/nchs/data/databriefs/db36.htm>

Stroke, the third largest killer of African Americans, is another condition that could possibly be prevented by proper health maintenance and routine medical visits. According to the CDC, the “risk of having a first stroke is nearly twice as high for blacks

than for whites, and blacks are more likely to die following a stroke than are whites (“Stroke in the U.S.,” 2015). Hypertension, hyperlipidemia (high cholesterol), and smoking are the three highest risk factors for stroke; and between the years of 2007 and 2010, the “largest prevalence of hypertension was among...African American adults...and those with diabetes, obesity” (“Health of Black,” 2015). Control of one’s blood pressure is vital when preventing stroke, and with education, medicine, and compliance with health regimens, hypertension can be well controlled.

Another major health problem that African Americans face is obesity. Obesity is a risk factor in heart disease, stroke, and diabetes- all major health killers of African Americans. From 2007 to 2010, “the prevalence of obesity among adults...was largest among African American compared with white...women and men, and the overall obesity prevalence (both sexes combined) of African American adults was also the largest prevalence compared with white...American adults” (“Health of Black,” 2015). There are both genetic and behavioral factors that contribute to obesity, but obesity can be overcome and prevented by acquiring good nutritional education and obtaining an appropriate individual physical exercise regimen.

Diabetes, the fourth leading cause of death in African Americans, disproportionately affects African Americans more so than white Americans. “In 2010, the prevalence of diabetes among African American adults was nearly twice as large as the prevalence among white adults” (“Statistics about Diabetes,” 2014). African Americans have the highest incidence of diabetes out of any other ethnic group with the exception of Mexican Americans (“Statistics about Diabetes,” 2014). There are two types of diabetes: Diabetes Mellitus Type I and Type II. Type I diabetes is a congenital type that is not

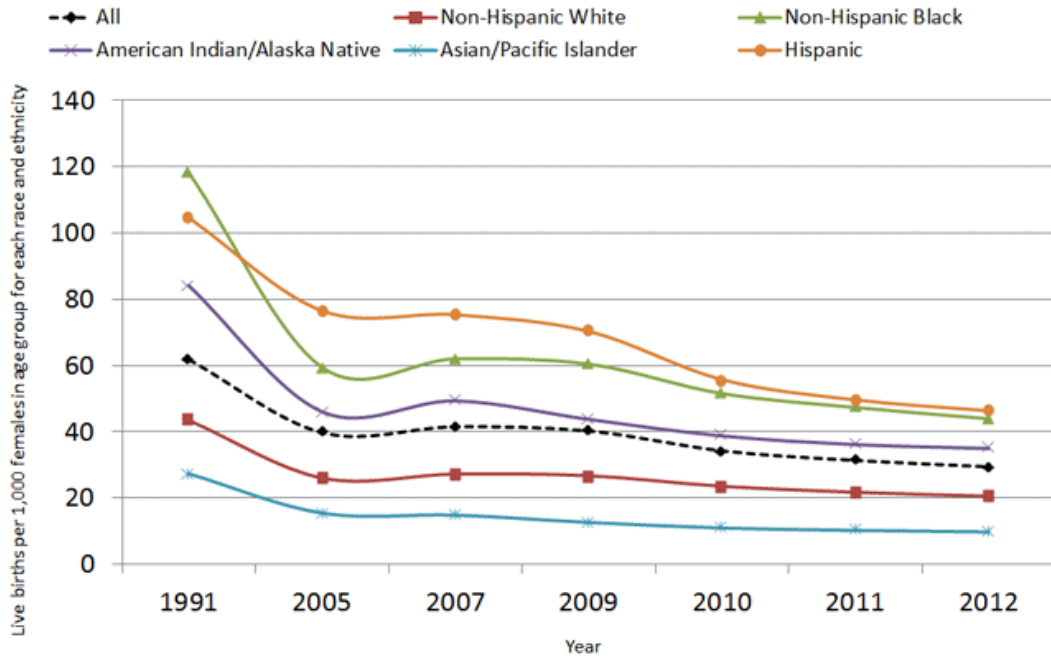
acquired by habits of the sufferer. Type II diabetes is acquired over time and results when either the pancreas stops secreting insulin or either when the body's cells stop responding to insulin. Many of the risk factors for developing Type II diabetes are preventable, such as obesity and immobility ("Statistics about Diabetes," 2014). Once one is diagnosed with diabetes, management of an optimal blood glucose level, or euglycemia, is key. Failure to maintain euglycemia, can result in complications, disability, and death. Some of the most common complications and comorbidities that can result from mismanagement of diabetes are hypertension, heart attack, stroke, blindness, kidney disease and amputations ("Statistics about Diabetes," 2014). According to the American Diabetes Association, "in 2009-2012, of adults aged 18 years or older with diagnosed diabetes, 65% had blood pressure greater than or equal to 140/90 mm Hg or used prescription medications to lower high blood pressure" ("Statistics about Diabetes," 2014). Adults with diabetes are 1.8 times more likely to be hospitalized with a heart attack than adults without diabetes and adults with diabetes are 1.5 times more likely to be hospitalized with stroke than adults without diabetes. Loss of eyesight is a potential complication of diabetes. "In 2005-2008, of adults with diabetes aged 40 years or older, 28.5% of people had diabetic retinopathy," since diabetic retinopathy can lead to blindness, it is a common cause of disability in people with diabetes ("Statistics about Diabetes," 2014). Kidney failure can be attributed to diabetes in that diabetes has a direct effect on the tubules of the kidneys. The kidneys have to expend more energy to filter the glucose out of the blood, which wears on them over time and causes them to fail. Amputations are other common occurrences in persons with uncontrolled diabetes. The American Diabetes Association reports that "in 2010, about 73,000 non-traumatic lower

limb amputations were performed in adults aged 20 years or older with diabetes” (“Statistics about Diabetes,” 2014). For such a widespread disease, diabetes is a very serious one that carries serious consequences. Since African Americans are more likely to acquire diabetes, all of the complications previously discussed are possible outcomes for those who fail to be diagnosed with diabetes or do not properly manage their diabetes. Fortunately, it is a disease that can be prevented, controlled, and sometimes eliminated when properly cared for under medical supervision.

Besides life expectancy, infant mortality rate is another indicator of the health status of a population. According to the CDC, “the mortality rate for ...black infants is more than twice that of...white infants” (“Teen Birth Rates,” 2015). One of the major causes of infant mortality in the African American community is preterm birth, birth before 37 weeks (“Teen Birth Rates,” 2015). A number of factors contribute to preterm birth, one of which being low maternal age. Younger mothers are more unlikely to carry their babies to term, and teenage mothers are more likely to be farther along in their pregnancy when they first seek prenatal care. They are also less likely to adhere to nutritional and medical advice (“Barriers to Prenatal,” 2015). The occurrence of younger mothers is more common in the African American community where the rate for teenage pregnancy is almost two times higher than for white teenagers (“Barriers to Prenatal Care,” 2015).

Figure 3-3.

Birth Rates (Live Births) per 1,000 Females Aged 15–19 Years, by Race and Hispanic Ethnicity, select years



1991-2011 rates from: Martin JA, Hamilton BE, Ventura SJ, Osterman MJK, Curtin SC, Mathews TJ. Births: Final data for 2011. *Natl Vital Stat Rep.* 2013;62(1): Table A.

2012 rates from: Martin JA, Hamilton BE, Osterman MJK, Curtin SC, Mathews TJ. Births: Final data for 2012. *Natl Vital Stat Rep.* 2013;62(9): Table A

CHAPTER IV

CURRENT IMPROVEMENTS IN HEALTHCARE RELATIONS

While the health status of African Americans is not at an optimal level, today African Americans have more options for accessing healthcare due to improved race relations, improved economic status, and healthcare advances that seek to make medical care more affordable and accessible for all Americans. Improved race relations have made African Americans less of a pariah of society. Laws that ended segregation and “separate but equal” allowed African Americans to be treated as equal citizens, able to obtain sufficient and equal healthcare. With the improved race relations came more opportunities for African Americans to advance economically, which further increased their access to adequate healthcare. For many, however, assistance was still needed. In 1965, President Lyndon B. Johnson signed the Medicare and Medicaid programs into law. The purpose of these programs was to combat the high costs of healthcare in an attempt to make healthcare more affordable for the masses. Around the time that the Social Security Act of 1965 was signed into law that made Medicare and Medicaid legal entities, a whopping 49.5% of the black population in America was below the poverty line (“Characteristics of the Population,” 1983). With the enactment of Medicaid and Medicare, the healthcare that much of the African American population was lacking then became attainable. Those with chronic diseases were able to get the regular, on-going care that was needed, and preventive services were obtainable without great financial strain.

But even with such advancement in the American healthcare system, some still run into problems with obtaining healthcare. Studies are showing that increasing numbers of doctors across the country are no longer accepting people with Medicaid as patients. According to a 2014 study released by the health care consulting firm Merritt-Hawkins, through a survey of doctors from a range of specialties from 15 different metropolitan areas, it was found that only 45.7% of the doctors were accepting Medicaid patients, a percentage that was down from 55.4% in 2009 (“Half of Doctors,” 2014). The study cites low Medicaid reimbursements and complicated billing as examples from a number of reasons that were given. As of 2014, Black Americans made up 21% of those receiving Medicaid benefits, which means that 1/3 of the African American population that is receiving Medicaid benefits risk being turned away from a growing number of physicians that are choosing not to treat those insured with Medicaid (“Black or African American,” 2015). A population with an already existing problematic health status now faces another healthcare obstacle.

But despite the grim statistics for those insured under Medicaid, further advances in the healthcare system promise even more opportunities for improved health. In March 2010, President Barack Obama signed the Affordable Healthcare Act (AHA) into law. The Patient Protection and Affordable Healthcare Act, informally known as ObamaCare, aims to lower the costs of private health insurance and improve the quality of healthcare and the services offered. According to the U.S. Department of Health and Human Services, many African Americans have already benefited from the new Affordable Healthcare Act. One improvement is as of 2014, “an estimated 5.1 million African American women with private health insurance now have guaranteed access to women’s

preventive services without cost-sharing” (“The Affordable Care Act,” 2015). Also, more than half a million African Americans between the ages of 19 and 26 who previously would not have had health insurance, are now able to be covered under their parents’ health insurance plan (“The Affordable Care Act,” 2015). The ACA is also attempting to make a difference in the health of those with chronic diseases, since insurers are no longer able to charge more or deny coverage to someone with a preexisting, chronic condition (“The Affordable Care Act,” 2015).

The government has made great strides in advancing healthcare to all Americans regardless of race or socioeconomic status. But despite the advancements that are made in healthcare there is still resistance on the part of some African Americans trust the healthcare system. In a 2006 qualitative study conducted at a public hospital in Chicago, a group of doctors sought to understand how African Americans viewed the trustworthiness of doctors and how it affected their propensity to seek care. To gather this data, the doctors held nine focus groups comprised of sixty-six African Americans of both genders. They then asked questions about how the participants felt about doctors pertaining to race, ethnicity, and mannerisms and what sparked trust and distrust. They found that many of the participants felt as if many doctors cared more about profit than they cared about healing the patient, which aided in distrust. Another source of distrust was the race of the doctor versus the race of the patient. The overwhelming majority of the participants claimed that they felt that white doctors cared more about the wellbeing of their white patients more than they did the wellbeing of their black patients. When the study’s conductors asked the participants if past history of medical misconduct in the African American community influenced their view of physicians, they were met with

numerous stories of family members and acquaintances that were rumored to have been experimented on in hospitals or doctors' offices. Many participants did admit that memories of stories that they had heard and historical events did play a part in their suspicion of physicians and some hesitance in trusting their doctors. In all focus groups, it was reported that the participants had some expectation of racism and financial discrimination during a doctors' visit. The doctors stated that their findings led them to conclude that there is, indeed, some distrust still looming in the minds of African Americans, and this distrust and anticipation of a negative experience makes one less likely to seek healthcare (Jacob et al., 2006). Other studies that have been conducted in the past 20 years have arrived to the same conclusion, citing a fear of racism and memories of past historical events as major reasons that many African Americans are hesitant to seek healthcare.

CONCLUSION

Given the history of unethical practices at the expense of African Americans and the legal and socially acceptable hindrances that were once in place to keep African Americans marginalized and without access to healthcare, it is increasingly clear why African Americans may be hesitant to seek the help of medical professionals. Over generations, an oral history of the medical experimentation, exploitation, and abuse that has plagued African Americans since colonial times has been passed down and planted the seeds of distrust and suspicion. The graphically true stories of racially motivated experiments, false treatments, and deception invoke a fear and a natural hesitancy to seek the help of those who have a long history of wrong doing. For this reason, African Americans have had the worse access to healthcare and the worst health status of any other ethnic group in the United States.

By the current health status of African Americans in comparison to white Americans and other ethnic groups, it is apparent that there has been a disconnect between the community and the healthcare system. The negative effects of the past have had negative effects on African American health status today. African Americans are among top when it pertains to bleak medical outcomes and negative health statistics. They are more often afflicted with diseases that can be prevented with regular health screenings and are more likely to die from those preventable diseases as a result of delayed medical care. While African Americans have increased access to healthcare more so than they did in the past, the effects of the past still linger. Although there are no

longer legal barriers that are keeping African Americans out of doctor's offices, there are still mental barriers such as memories of Tuskegee, Alabama and the stories of "Mississippi appendectomies" that keep people shying away.

In the nursing profession, it is important to be mindful of barriers that may affect the health of the public and work towards removing those barriers to improve patient health. Maintaining ethical integrity in nursing research studies prevents the reoccurrence of ethical violations and builds trust between patients and healthcare providers. Also, respect for cultural differences is vital to providing sufficient patient care. Education is the key to overcoming the distrust of the healthcare system. Education is required by healthcare consumer, as well as the healthcare provider. It is important for the healthcare consumer to know the past, but to also realize the advancements made in the healthcare system to provide the equal and competent medical care for every citizen. Additionally, it is necessary for nurses and physicians to be informed of past ethical deficiencies, and become culturally aware of the misconceptions or concerns that their patients of different racial backgrounds may have. Ongoing education emphasizing ethics and cultural diversity heightens the awareness of healthcare providers and provides for a more trusting environment. Together, a commitment to ethical practices, improved cultural competency, and a desire for progression will lead to improved health of the African American community.

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