

RACE-BASED MEDICINE:
A CASE FOR COMPETENCY AND SOLIDARITY
IN MINORITY COMMUNITIES

A dissertation submitted to the Caspersen School of Graduate Studies
Drew University in partial fulfillment of
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ABSTRACT

Race-Based Medicine:
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Doctor of Medical Humanities Dissertation by

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In 2005, The United States Food and Drug Administration's (FDA) approval of BiDil, "the black heart failure drug," created false perceptions of tailored research, technology and therapeutic intervention for specific racial groups by resuscitating race as a proxy in medicine. Unlike other heart failure drugs, BiDil is specifically targeted to treat the African American community. Compared to other races, African Americans suffer from disproportionately higher rates of heart failure. BiDil shapes race as the primary indicator for the predispositions to certain diseases. BiDil is categorized as race-based medicine (RBM) or race-specific medicine. Race-based medicine or race-based therapeutics is the process by which pharmaceutical companies create a drug that is specifically made for a selected racial group.

Race-based medicine has been used and defended in therapeutic intervention to treat minorities that have diseases or illnesses that are prevalent in their specific group. This development cannot be solely explained by scientific medicine, but rather participates in a long history of racial discourse in cardiology. Race-based medicine is not a ground breaking concept but a recycled idea founded out of the American Eugenics Movement (AEM), from the mid-nineteenth century to the mid-twentieth century.

The FDA's approval of BiDil has sparked controversy in the use of race-based medicine. Race-based medicine can stigmatize racial groups by attributing and imposing certain diseases and behavioral traits. It can also exploit racial groups, in a market-based pharmaceutical culture, by capitalizing on racial identity. It misconstrues the distinctions of race, ancestry and genetics by promoting assumptions that race alone is the marker of disease, which inaccurately influence scientific studies and research. Race-based medicine is not the way to solve prevalent diseases in racial groups but the awareness and acknowledgement of the predispositions and socioeconomic inequities existing in minority groups. Furthermore, one needs to acknowledge human ancestral groups and geographical conditions can contribute to specific diseases that affect racial groups. This dissertation will examine the ways in which race is not an accurate proxy for basing therapeutic intervention and will examine various applications of race-based medicine that undermine minority communities' health with clinical and theological solutions as a response.

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INTRODUCTION

Race-based medicine is the process pharmaceutical companies use to assign specific drugs to racial groups. The idea of race-based medicine asserts that racial groups are biologically different. Therefore, drugs, tailor made for racial groups, is the best means for efficacious treatment within minority populations. For example, let's use a headache as an ailment. If an African American, Hispanic, and white individual followed the practice of race-based medicine, they would need an African American, Hispanic, and white aspirin to alleviate discomfort. However, such racially coded aspirin is not beneficial because a headache is not innately different due to anyone's racial classification. Illnesses and diseases do not discriminate. When all individuals take the same aspirin, the time it will take to alleviate the pain may vary due to each individual's response to pain and medicine internally but the reaction to the aspirin is not dependent on external traits.

Consequently, the use of race-based medicine fragments racial groups. Its use attributes behavioral traits, labels, stereotypes and diseases which can stigmatize minority groups. Also, it can lead to prejudice and discrimination in the clinical practice. Race-based medicine misconstrues the distinctions of race, ancestry and genetics by promoting assumptions that race alone is the marker of disease, which inaccurately influence scientific studies and research. Race-based medicine is not the way to solve prevalent diseases in racial groups. Health disparities can be alleviated by the awareness and acknowledgement of predispositions and socioeconomic inequities existing in minority groups. This dissertation examines the ways in which race is not an accurate proxy for

basing therapeutic intervention and how race-based medicine undermine minority communities' health.

Chapter one uses methods of the history of medicine, law, politics, genetics, and sociology exploring the origins of race-based medicine through eugenics. Eugenics was influenced by French Biologist Jean Baptiste de Lamarck and Charles Darwin. Francis Galton, Charles Darwin's cousin, developed the phrase Eugenics. There are two schools of eugenics: positive eugenics and negative eugenics. Positive eugenics asserted human breeding should be controlled to produce genetically superior human beings. Negative eugenics asserted the improvement of humanity can only happen by eliminating or excluding genetically inferior human beings.

Charles B. Davenport, the Father of American Eugenics, established and directed The Eugenics Record Office. Davenport redefined eugenics as “the science of the improvement of the human race by better breeding”¹ to accomplish eugenics “we apply science to the problems of a class-ridden and socially heterogeneous society.”² All eugenic influencers were exclusively self-identified as “White,” “Anglo Saxon,” “Nordic,” or “Caucasian” stressing the idea of their racial superiority. Davenport categorized Africans, African Americans, Indians, and Indigenous tribes were “genetically unfit” or inferior because they were less intelligent and primal. Davenport's racial classification was the first official American categorization of races. Davenport's 1908 Inheritance in Canaries study influenced the idea of disease and intelligence being

¹ Stern, Alexandra. *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America*. Berkeley: University of California Press, 2005, 11.

² Sussman, Robert W. *The Myth of Race: The Troubling Persistence of an Unscientific Idea*. Cambridge: Harvard University Press, 2014, 55.

associated to certain racial groups,³ which created the notion of race-based medicine. As a result, eugenics' ideology embraced sociomedical racialism meaning diseases were classified and attributed to certain races.⁴ Eugenic influence created social and racial classifications through pathology. Specifically, African Americans with Sickle Cell Anemia (SCA) and Jews with Tay Sachs Disease (TSD).

To be clear, eugenics did not solely dehumanize African Americans and Jews. Slavs, Italian, Polish, Irish, Asian, Turks, and Greeks were included in socially unfit classifications. However, there was a particular paranoia of an American epidemic with individuals with SCA and TSD. SCA affect groups from Indian, Asian, Saudi Arabian and Mediterranean backgrounds, but SCA was deemed a "black disease" due to the medical science, medical literature, and anthropological eugenic influences. SCA was perceived as a plague brought by black people but factually it was immunity toward malaria.

The fear of SCA lead to the notion of Jim Crow (separate but equal) Medicine which led to segregated blood banks by the American Red Cross in WWII.⁵ Neurologist Dr. Isador H. Coriat alleged TSD nerve cells contained poison that was transmitted through Jewish mother's milk.⁶ SCA and TSD social fear of contagiousness abused

³ Largent, Mark A. *Breeding Contempt: The History of Coerced Sterilization in the United States*. New Brunswick, N.J.: Rutgers University Press, 2008, 48.

⁴ McBride, David. *From TB to AIDS: Epidemics Among Urban Blacks Since 1900*. Albany: State University of New York Press, 1991, 19-20.

⁵ Wailoo, Keith. *Drawing Blood: Technology and Disease Identity in Twentieth-Century America*. Baltimore: Johns Hopkins University Press, 1997,150.

⁶ Reuter, Shelley Z. "The Genuine Jewish Type: Racial Ideology and Anti-Immigrationism in Early Medical Writing about Tay-Sachs Disease." *Canadian Journal of Sociology*. 31, no. 3 (Summer 2006), 298.

African Americans and Jews through sterilization and its forms of population control, birth control, marriage control, and immigration policies.

Chapter two uses the methods of medical anthropology, clinical ethics, physician-patient relationship, biology and sociology to explore the misappropriations of the black body, race-based experimentations, consequences of misappropriations about the black body and the black community's response to false associations and harmful treatment. The eugenic perceptions, of the "black body," produced misappropriations and falsified theories of the anatomy and biology of black individuals. The ideologies of African Americans being "lesser than" or "inferior" transferred into the fields of anthropology, anatomy, and biology creating myths of innate human differences. The understanding that black bodies were innately different produced the terms "black hardness" and "black durability," which affirms blacks have the innate capacity to endure or tolerate extreme conditions or illnesses. It was thought the experience of slavery made African Americans evolve to be a people of great endurance and stamina.

Such ideologies asserted black skulls were so thick that the skull would bruise or break the slave-owner's hand if he punched a slave⁷ or longer limbs and shorter trunks was the reason why blacks could run faster than any group. Black hardness led to the infatuation of the black body that created unconscionable harm in the clinical practice. As a result, J. Marion Sims, the father of gynecology, performed painful procedures on slave women without anesthesia.⁸ The US government mustard gas experiments on blacks and

⁷ Hoberman, John M. *Darwin's Athletes: How sport has damaged black America and preserved the myth of race*. Boston: Houghton Mifflin Co., 1997, 176.

⁸ Fett, Sharla M. *Working Cures: Healing, Health, and Power on Southern Slave Plantations*. Chapel Hill: University of North Carolina Press, 2002, 151.

Hispanics which caused immediate and severe eye injuries, burns, oozing sores and blistering on the face, hands, underarms, buttocks, and genitals, which resulted in “lung damage, psychological disorders, cancer, asthma, eye problems, and blindness.”⁹ Sloan-Kettering Institute’s Dr. Chester M. Southam injected over 180 black Ohio State Prison’s inmates with live human cancer cells to see how a healthy human body would react to cancer cells.¹⁰ Such experiences remain in the psyche of the black community through a key means of communication called oral tradition. As a response to race-based experimentation and race-based medicine, slaves created black homeopathy a medical system that offers herbal, botanical, traditional, psychological, and spiritual approaches to medicine.¹¹

Chapter three uses the methods of history of medicine, genetics, clinical ethics, research ethics, pharmacology, physician-patient relationship and sociology to assess significant heart studies before BiDil “the black heart failure drug,” BiDil’s process to approval and its influence regarding race in the areas of economics, medicalization, and genetics with suggestions of physician involvement and nutrition as better solutions for health inequity. There are numerous problems with BiDil. The data out of BiDil’s clinical trials were based on unclear data because there was no control group to prove the drug was efficacious. BiDil was a rushed drug only taking five years to be in the market with insufficient funding. BiDil cost three times more than any other drug in its class, which does not benefit African Americans who are socioeconomically disadvantaged.

⁹ Smith, Susan L. “Mustard Gas and American Race-Based Human Experimentation in World War II.” *Journal of Law, Medicine & Ethics* 36, no. 3 (Fall 2008), 518.

¹⁰ Washington, Harriet A. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. New York: Doubleday, 2006, 252.

¹¹ Covey, Herbert C. *African American Slave Medicine: Herbal and Non-Herbal Treatments*. Lanham: Lexington Books, 2007, 42.

The idea of BiDil medicalizes race, a nonmedical issue, and interprets, defines and treats race as medical a problem, which creates stigmas, stereotypes, and behavioral traits that is rooted in eugenic ideas. Finally, self-identification of one's race has no contextual validity, poor proxy of other people's perception, excludes people who cannot self-identify (i.e. multi-racial or bi-racial individuals), no use related to research questions on ancestry, and does not reflect the descent and ethnic origin of individuals.¹² BiDil an overly priced "quick fix" is not an adequate solution to health inequities in minority communities.

Race is a myth. Therefore, race should not be a proxy for disease. We are all genetically similar. For example, human genomes are 3 billion base pairs spread across 23 chromosomes are 99.9% similar to one another with 0.1% difference (3million pairs) with a smaller selection of 0.1% provide the raw material for locating the source of difference.¹³ A more practical means for alleviating health inequity is improving physician's cultural competency, empathy and awareness with a keen focus on diet and nutrition.

Chapter four uses the methods of theology, textual criticism, exegesis, eisegesis, black church history and combining biblical and medical narrative to examine race in biblical literature, scripture as a tool for minority patient empowerment, and examples of the black church and personal clergy role in health advocacy. Black theology analyzes the oppression of black people, affirms the personhood of black people, and advocates their

¹² Whitmarsh, Ian, and David S. Jones. *What's the Use of Race?: Modern Governance and the Biology of Difference*. Cambridge, Mass: MIT Press, 2010, 128.

¹³ Wailoo, Keith, Alondra Nelson, and Catherine Lee. *Genetics and the Unsettled Past: The Collision of DNA, Race, and History*. New Brunswick, N.J.: Rutgers University Press, 2012, 16.

social and political liberation.¹⁴ Black theology as survival theology is a response to the labels of race and illness by liberating minority communities to participate and speak out against the stigma of racial disease. Black theology is a tool that demonstrates multiple black perspectives and experiences. In contrast, race-based medicine encourages a truncated look at black experiences. Race-based medicine does not look at the totality of the African American pathological experience rather it irrationally uses drugs as an inadequate solution toward health equity.

Black theology defines empowerment and justice of African Americans in race-based environments that is rooted in and thrives on oppression. Blacks replaced dehumanizing identifications of race-based medicine and biblical literature with the belief that they were created by the same God with equal value. Black theology condemns race-based medicine because it separates racial groups as different beings through the construction of race. Furthermore, black theology asserts it does not matter what skin color you are we are all human beings and come from the same God.

As a response to race-based medicine, I suggest scripture can be used as an effective aid by the illness narratives in the gospels. For example, I connect the biblical and medical narrative of the leper in Galilee (cf. Mark 1:40-45) being denied healing in the temple with blacks being denied healing in white hospitals but responded through the Black Panther Party's People's Free Medical Clinics emphasizing "completely free health

¹⁴ Sanders, Cheryl J. "European-American Ethos and Principlism: An African-American Challenge." *On Moral Medicine: Theological Perspectives in Medical Ethics*, edited by Stephen E. Lammers and Allen Verhey, Wm. B. Eerdmans Publishing, 2012, 78.

care for all black and oppressed people.”¹⁵ Also, I reflect on past and current black church health movements to continue the push for health equity in communities of color. As mentioned in chapter three, the patient-physician relationship and diet and nutrition are suggested ways to improve health in minority communities. However, the black church has a unique position creating dialogue in medical, religious, and theological settings on how race-based medicine and health disparities affect minority communities and ways the black church can respond through biblical inspiration and church advocacy.

¹⁵ Nelson, Alondra. *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination*. Minneapolis: University of Minnesota Press, 2011, 4.

Chapter 1

RACE-BASED MEDICINE'S ORIGIN

Race-based medicine (RBM) or race-specific medicine asserts that race, understood as a biological reality and isolated from structural dynamics of discrimination, is the primary indicator for the predispositions of certain diseases. Race-based medicine is not a ground breaking concept but a recycled idea based out of the eugenics movement. Eugenics promoted specific social policies, ideologies, and biological classifications we ought not revive in the twenty first century. Sickle Cell Anemia (SCA) a non-fatalistic disease primarily (but not exclusively) effecting Africans and African Americans was the first hereditary disease examined in the eugenics era with Tay Sachs disease (TSD) to follow.¹⁶ The father of race-based medicine Linus Pauling (1901-1994) was a key figure in the eugenic era officially identifying SCA as a black person disease creating and revolutionizing molecular biology. This chapter will examine the roots of race-based medicine through eugenic influences and how eugenics socially affected minority communities who possessed Sickle Cell Anemia and Tay Sachs Disease.

Eugenic Origins

In the early nineteenth century, French Biologist Jean Baptiste de Lamarck (1744-1829) formulated his cornerstone theory of inheritance of acquired characteristics called Lamarckism, which affirmed, “environmental forces, both favorable and unfavorable,

¹⁶ SCA and TSD are diseases that are prevalent in numerous racial groups. They are not homogeneous diseases. I will expound more on SCA and TSD and their relation to racial groups later in this chapter.

could alter human heredity and be transmitted down the familial line.”¹⁷ Lamarck’s theory influenced Robert Knox’s *Races of Man* (1850), Arthur Gobineau *Essai sur l’inégalité des races humaine* (1853) and Friedrich Max Muller’s idea of an Aryan race (1853).¹⁸ Lamarck’s idea was imbedded in the belief of degenerationism, which focused on the development of vestigial organs (i.e. tailbone and wisdom teeth). On an important note, a similar theological view of degenerationism called polygenism was prevalent around the sixteenth century. Polygenism suggests the human race has descended from two or more ancestral types. I will discuss polygenism in detail in chapter four. Degenerationism raised the fear that certain organs will lose their function and structure by each passing generation. Lamarck most influential follower was Neo-Lamarckian Charles Darwin.

On November 24, 1859, English Naturalist Charles Robert Darwin’s book *The Origin of Species* quickly became a significant work of modern biological theory. He stressed the use, neglect and deterioration in organ development including how the environment acts directly on organic structures, which described an organism’s livelihood and environment. The two key theories from Darwin’s work were evolution and natural selection. Evolution is a biological theory suggesting all types of living beings have their origin in other preexisting beings and distinguishable differences resulted from modifications in successive generations. Natural selection is the process that results in the adaptation of an organism to its environment by means of selectively

¹⁷ Stern, *Eugenic Nation*, 14.

¹⁸ Bethencourt, Francisco. *Racisms: from the Crusades to the twentieth century*. Princeton University Press, 2014, 276-288.

reproducing changes in its genotype, or genetic constitution. Evolution and natural selection were the foundational tools in the development of Social Darwinism.

Consequently, the idea “might makes right” preceded before *Origin*.¹⁹

Surprisingly, the “survival of the fittest” ideology did not come from Darwin but from social philosopher Herbert Spencer, who created the phrase in 1864 and professed, “This survival of the fittest, which I have here sought to express in mechanical terms, is that which Mr. Darwin has called ‘natural selection,’ or the preservation of favoured races in the struggle for life.”²⁰ Spencer’s idea was adopted into Social Darwinism and developed into its own influence and interpretation for racial survival. Through Social Darwinism, it was wrong and unethical to help the weak because such actions aid the survival and reproduction of the less fit, which threatens the progress and survival of the strong and equipped. Social Darwinism asserted the strongest or the fittest should flourish in society. Darwinism brought the idea to a level of unprecedented consciousness. Darwin made his mark on biology but it is equally fitting to point out Spencer was a huge voice in the late nineteenth century, suggested ideologies continued evolution of groups and individuals to a higher level from generation to generation naturally without any interference by any institution. Spencer sold over one million books in his lifetime.²¹

Darwin and Spencer’s theories set the foundation for an emerging movement that would change the concept of American life called Eugenics. Eugenics is the belief or study in the possibility of improving the qualities of the human species or a human population. Its creator Francis Galton, Charles Darwin’s cousin, developed the phrase

¹⁹ Sussman, *The Myth of Race*, 48.

²⁰ Ibid.

²¹ Ibid., 49.

Eugenics formally called “Race Hygiene” in 1883; Eugenics in the Greek “*eu*” (well or good) and “*genesis*” (to come into being, be born).²² Galton believed the control and breeding of humans was a possible goal through the use of statistics. In the *Macmillan’s Magazine* and book *Hereditary Genius* Galton defended his stance for nature over nurture.²³ He spent his next forty years of life advocating the use of eugenics in society.

Galton stressed the concept of eminence for a better society. Eminent individuals are groups possessing high ranking, distinguished, or prominent socioeconomic statuses in society. Eminent pedigree had to do with environment, culture, and education. In Galton’s mindset, eminent humans produce more eminent humans and vice versa for “mediocre” humans. Galton used the 1865 edition of *Dictionary of Men of the Time* and obituaries to record the eminence of individuals. Galton, “estimated that 1 in 4,000 men in Britain qualified as eminent. Close relatives of the eminent are much more likely to be eminent than are distant ones.”²⁴ Galton continued his statistical work with his pupil Karl Pearson.

Along with his mentor, Karl Pearson revived Austrian Monk and Botanist Gregor Mendel’s hereditary laws by a developed “biometrical” approach. Mendel created the theory called “unit characteristics” (now called genes by his research) with peas in his monastery’s garden. Mendel believed genes did not go through different stages but genes are transferred as separate and distinct units from one generation to the next.²⁵ Mendel’s research resulted in his conclusion that planting two tall plants will produce a tall plant

²² Stern, *Eugenic Nation*, 11.

²³ Hansen, Randall, and Desmond S. King. *Sterilized by the State: Eugenics, Race, and the Population Scare in Twentieth-Century North America*. New York: Cambridge University Press, 2013. 29.

²⁴ Ibid.

²⁵ Ibid., 32.

and the same result will happen with short plants. Furthermore, he assumed a tall and short plant would produce an average size plant but to his surprise a tall plant was produced. Mendel's observations concluded some genes were dominant and some genes were recessive, which led to his famous 3:1 ratio producing thousands of variations of short peas. Mendel's findings resulted in a different approach to eugenics. Instead of the exclusive statistical approach for hereditary superiority (Galton), Mendel's experimental breeding was another means to do eugenic work.

Pearson partnered with Cambridge biologist Walter F.R. Weldon to continue Galton's research efforts. Pearson and Weldon had a total of fourteen years of work together, which resulted in one hundred published scientific papers, the production of the journal *Biometrika* promoting biometrical approaches, and the reconciliation of Galton's statistics and eugenics. Pearson and Weldon's professional partnership aided Galton to open Britain's Eugenics Record Office (BERO)²⁶ and an endowed research chair in eugenics at the University College London, in 1904. Galton's promoted eugenics' influence by the founding of The Society of Race Hygiene (1905), and the British Eugenics Society (1907).²⁷

Darwin, Spencer, Galton, Pearson, and Weldon's work produced two schools of eugenics: positive eugenics and negative eugenics. Positive eugenics asserted human breeding should be controlled to produce genetically superior human beings. Negative eugenics asserted the improvement of humanity can only happen by eliminating or

²⁶ Hansen, et al., *Sterilized by the State*, 32.

²⁷ Sussman, *The Myth of Race*, 51.

excluding genetically inferior human beings.²⁸ Galton was a positive eugenicist. Negative eugenics was more accepted in theory and practice in the United States, which became the blueprint for the German Eugenics Movement influencing the justification of the Holocaust. American Geneticist and Zoologist Charles B. Davenport visited London and dined with Galton, Pearson, and Weldon.²⁹ The meeting dramatically changed Davenport's ideologies of biology. His book, *Statistical Methods with Special Reference to Biological Variation* was primarily influenced by Galton and Pearson. Davenport's encounter with the founding fathers of eugenics changed American social policy and biology in the early twentieth century and established Davenport as the father of American eugenics.

Davenport's influence in America was unrivaled. In 1904, Davenport received a grant from the Carnegie Institution to establish and become director of the Station of Experimental Evolution at Cold Harbor on Long Island, which performed breeding experiments on animals and plants.³⁰ Specifically, he focused on genetic make-up of family pedigree differing from Galton who focused on external characteristics. Through his grant, Davenport developed a record of families by sending surveys and questionnaires to public institutions (i.e. high schools, colleges, and churches). He received hundreds of survey results which Davenport concluded, "insanity, epilepsy, alcoholism, pauperism (poor/poverty), and especially feeble-mindedness (mental incompetence or deficiency) were all hereditary conditions."³¹ His goals for eugenics

²⁸ Sussman, *The Myth of Race*, 50.

²⁹ Hansen, et al., *Sterilized by the State*, 33.

³⁰ Ibid., 34.

³¹ Ibid.

progressed to a wider scale as he mapped out the genetic health of the entire United States.

In 1909, Davenport meets with Psychologist Herbert H. Goddard (the first translator of the Binet-Simon intelligence tests into English) and encouraged Goddard to read British Biologist and creator of the Punnett Square R.C. Punnett's 1909 book *Mendelism*. The Binet-Simon intelligence tests were from French physicians Alfred Binet and Theodore Simon to evaluate which children needed assistance in class. Davenport convinced Goddard feeble-mindedness in children and other inherited conditions are caused by "unit characteristics" (genes) traced by family genealogy. The Binet-Simon intelligence test was the key influence in American standardized testing and the skewed procedure that characterized individuals with mental difficulties defined by eugenics.

In 1910, Davenport, with the aid of a huge donation from the widow of a railroad tycoon E.H. Harriman, established and directed The Eugenics Record Office (ERO) with Harry H. Laughlin as superintendent. The ERO instantaneously became the mecca for eugenicists, eugenics research, social policy, publication, and propaganda. In 1911, Davenport redefined eugenics as "the science of the improvement of the human race by better breeding"³² to accomplish eugenics "we apply science to the problems of a class-ridden and socially heterogeneous society."³³ After Davenport and Laughlin, there were many Eugenicists who shaped American and European culture like Irving Fisher (founder of the American Eugenics Society), Margaret Sanger (founder of the Planned Parenthood

³² Stern, *Eugenic Nation*, 11.

³³ Sussman, *The Myth of Race*, 55.

Movement), Alfred Ploetz (founder of German Eugenics), Eugen Fischer (German Eugenic Anthropologist), and Fritz Lenz (German Race Hygienist).³⁴

All eugenic influencers were exclusively self-identified as “White,” “Anglo Saxon,” “Nordic,” or “Caucasian” stressing the idea of their racial superiority compared to other externally different groups or races. Davenport categorized Africans, African Americans, Indians, and Indigenous tribes were “genetically unfit” or inferior because they were less intelligent and primal. He also concluded that racial intelligence was absolute:

In their mental traits... different peoples are unlike. It has formerly been maintained that the obvious mental differences in races are due to differences of education and training merely, but the experience with native tribes in Australia and Africa has shown that the children of these people do not respond in the same way as the white children to the same education... [T]he army intelligence test... showed that there is a marked difference in average mental capacity between the major races of mankind, and even between the peoples of different parts of Europe... In fact, it seems probable that in the same country we have, living side by side persons of advanced mentality, person who have inherited the mentality of their ancestors of the early Stone Age, and persons of intermediate evolutionary stages.³⁵

Davenport’s racial classifications determined the school you went to, what cemetery you will be buried in, where you live, your fertility control, and who you married, which created the first official American categorization of races.³⁶ Davenport influenced, The United States Office of Management and Budget (OMB). OMB constructed racial and ethnic categories used to collect, organize, and analyze the country’s demographic data. His classification of race combined with his interests in

³⁴ Hansen, *Sterilized by the State*, 37-47.

³⁵ *Ibid.*, 57.

³⁶ *Ibid.*, 56.

Mendelism suggested race not only affected intellectual ability, but human ailments and diseases (i.e. hemophilia and Huntington's chorea).³⁷ Davenport's findings were based on his 1908 *Inheritance in Canaries* study,³⁸ which influenced the idea of disease and intelligence being associated to certain racial groups.

Eugenics has informed therapeutic intervention toward diseases and illnesses that are prevalent in specific minority groups. Race-based medicine has the same principle. Eugenics ideology (and later continued through race-based medicine) embraced what Dr. David McBride called sociomedical racialism; diseases were classified and attributed to certain races.³⁹ Through eugenics justification, diseases and illnesses associated with certain racial groups should be treated because not only the disease affects that specific group, but it affects the entire society's environmentalism. Environmentalism is the, "social neutrality of infectious microbes, maintaining that immediate living conditions, employment experiences, dirt, and availability of health care were the primary determinants for the variation of disease rates among blacks and whites."⁴⁰ Eugenic influence created social and racial classifications through pathology.

In the early twentieth century, eugenic perceptions of African Americans as genetically unfit, inferior, and mentally incompetent resulted in a constructed perception of black folks as a national health threat. Eugenic concepts were used to influence disease diagnosis on a racial, biological and political landscape. Eugenics left African Americans associated with the "socially unfit:" criminals, insane, alcoholics, feeble-minded,

³⁷ Largent, *Breeding Contempt*, 47.

³⁸ *Ibid.*, 48.

³⁹ McBride, *From TB to AIDS*, 19-20.

⁴⁰ *Ibid.*, 48.

constitutionally weak, paupers, epileptics, deaf and blind, deformed, and individuals with specific diseases like Sickle Cell Anemia (SCA).⁴¹ To be clear, eugenics did not solely dehumanize African Americans. Slavs, Italian, Polish, Irish, Asian, Turks, Greeks and Jewish groups were included in socially unfit classifications. For the sake of race-specific diseases within minorities, SCA among African Americans and TSD among Jews will be the focus of this chapter. It is important to acknowledge the medical axioms of Tuberculosis (TB), Syphilis, Malaria, Diphtheria, Pneumonia, and Typhoid fever affected African Americans in American public health.⁴² Yet, the first disease to influence racialized medicine was SCA.

Sickle Cell Anemia

The A.D.A.M. Medical Encyclopedia states SCA is caused by an abnormal type of hemoglobin; a protein inside red blood cells that carries oxygen. SCA falls under hematology which is the study of blood and blood diseases. Before any Western recognition of the disease, Indigenous African tribes had different descriptions of SCA symptoms using phrases like, “the Ga tribe’s *Chwechweechwe*, the Fante tribe’s *Nwiiwii*, the Ewe tribe’s *Nuiduidui*, and the Akan tribe’s *Ahotutuo*.”⁴³ The Ga, Fante, Ewe, and Akan tribes are based out of Ghana. These phrases were used to describe the continued distressing pains caused by SCA. Africans were not concerned about the disease itself but with the chronic pain the disease SCA caused to fellow tribe members. In contrast, Western culture was more concerned with the disease as a public health concern for the

⁴¹ Sussman, *The Myth of Race*, 70.

⁴² Wailoo, Keith. *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health*. Chapel Hill: University of North Carolina Press, 2001, 55.

⁴³ *Ibid.*, 5.

well-being of those individuals eugenically and socially accepted. In the early twentieth century, American medicine rediscovered SCA through Dr. James B. Herrick.

On September 5, 1904, a twenty year old Grenadian dental student, Walter Clement Noel was rushed to Chicago's Presbyterian Hospital with respiratory problems. James B. Herrick, MD and his intern Ernest E. Irons, MD were on call. Irons took blood samples that had, "many pear shaped and elongated forms – some small."⁴⁴ Irons showed Herrick the unique examples of the blood smear. To his surprise, Herrick continued to monitor Noel for the next few years. Late 1905, Herrick uncovered German Pathologist M. Lowit discovery of odd shaped cells he called *sichelformiger* or sickle-shaped in appearance.⁴⁵ In 1909, Hematologist Russell L. Haden was the first to interpret SCA as a form of anemia and not a new blood disease. A step behind Haden, Herrick later used Lowit's terminology in the November 1910 issue of *Archives of Internal Medicine*, which made Noel's case the first recorded and documented case of SCA. Herrick deemed SCA unsolved after his publishing, which did not stop the curiosity of SCA to continue in the medical community.

In 1911, Benjamin Earl "B.E." Washburn wrote about SCA in the February issue of the journal *Virginia Medical Semi-Monthly*. Washburn reported about a patient Ellen Anthony at the University of Virginia Hospital with unusual looking blood cells. Washburn's report was the second reported case of SCA. The study and interest of SCA was growing modestly within the medical community and society as a whole. The concern was a result of the fear of a pandemic rather than the health and wellness of

⁴⁴ Savitt, Todd Lee. *Race and Medicine in Nineteenth- and Early-Twentieth-Century America*. Kent, Ohio: Kent State University Press, 2007, 18.

⁴⁵ *Ibid.*, 25.

African Americans who were viewed as “less genetically fit.” The future of America depended on the understanding and control of the Black health threat. An idea that came from health statistician Fredrick L. Hoffman in his 1896 study *Race Traits and Tendencies of the American Negro* and *The Surgical Peculiarities of the Negro* by surgeon Rudolph Matas, which were the, “standard references for medical and sociological research through World War I postulating race distinctions as the basis for the black-white health discrepancy.”⁴⁶ Hoffman’s publishing influenced an ideology that race was the cause of health disparities, which influenced Davenport’s racial and hematological classifications.

Davenport established distinctions within citizenship and racial categories. However, Viennese doctor and Nobel laureate Karl Landsteiner around 1901 established blood types A, B, O, M, N, and MN.⁴⁷ These blood characteristics were used to phenotypically classify “races” or “nationalities” as unique populations or expressions of their particular blood group. Landsteiner’s discovery influenced Anatomic-genetics which came from the Mendelian tradition emphasizing the importance of physiology and genetics within the black-white disease disparity. Genetic race traits were the basis for differing black and white disease mortality patterns.

In 1915, Major USA Army Medical Corps Robert W. Shufeldt published *America’s Greatest Problem: The Negro*. Shufeldt’s study produced research that suggested the inferiority of black folks. He felt social and economic equality for blacks

⁴⁶ McBride, *From TB to AIDS*, 16.

⁴⁷ *Ibid.*, 50.

were not important but the health issues that would be created by the black community was a top priority:

The gravest problem to be faced in dealing with the.... Negro is not his or her industrial future or right to social equality with the white man or woman. It is the danger to the public of his or her contagiousness and infections from the standpoint of physical and moral disease.⁴⁸

Shufeldt did not define himself as a eugenicist but his idea of African Americans and their health was exactly aligned with eugenic principles. Hoffman, Matas, and Shufeldt were among numerous influencers in encouraging race-specific initiatives to treat African Americans in the public health sector of the early 1900s. For example, in the 1910s Henry Hazen and in the 1920s Henry R.M. Landis focused on TB among African Americans. Also, in the 1920s J.H. Masum Knox brought awareness of pediatric epidemiology for African American children.⁴⁹ Race-specific interests were developing ideas that race and disease were synonymous with each other. Ironically, Hoffman's, Matas', and Shufeldt's influence in minority specialization was not a form of beneficence (doing good) toward minority patient care but an eugenic act to prevent a pandemic crisis caused by the Negro.

The technique that heightened targeted disease classification toward race was Victor Emmel's blood test. In 1916, Victor Emmel, an anatomist at the University of Washington, created a blood technique that was a central method for identifying and detecting sickled cells. SCA affect groups from Indian, Asian, Saudi Arabian and

⁴⁸ McBride, *From TB to AIDS*, 17.

⁴⁹ *Ibid.*, 58-63.

Mediterranean backgrounds,⁵⁰ SCA was deemed a “black disease” due to the medical science, medical literature, and anthropological eugenic influences. SCA was perceived as a plague brought by black people but factually it was immunity toward malaria. Since SCA was viewed a disease exclusively possessed by African Americans, individuals with SCA were instantly categorized as a black individual. Emmel’s test was used to justify Eugenicist Walter A. Plecker’s “One Drop Rule,” meaning one drop of Negro or Black blood makes you Black. After 1917, SCA changed from a clinical identity to a technological one.⁵¹ Emmel’s test meshed race and disease with identity.

Most doctors in the 1920s and 1930s used Emmel’s test as an assumption of blood and race. The tendency for blood to sickle (meaning the red blood cells are shape like a crescent) was defined by Virgil P. Sydenshicker (1923) a latent disease quality present in “Negro Blood.” Sydenshicker was from the University of Georgia Medical Department and characterized sickling in two forms active and latent. Active sickling was characterized by anemia joint pain, muscle pain, and severe abdominal discomfort with leg ulcers. Latent was characterized with no symptoms of anemia, but had rare rheumatic attacked and abdominal pain.⁵² John Hopkins physician John Huck (1924) defined sickling in three groups. First, a symptomless person had blood cells sickled after 24 hours with no symptoms. Second, a mild person occasionally had symptoms. Third, a

⁵⁰ Balgir, R. S. “Indigenous and Independent Origin of the B*-Mutation in Ancient India: Is it a Myth or Reality?” *Mankind Quarterly*. 42, no. 2 (Winter, 2001), 108-109.

⁵¹ Wailoo, *Drawing Blood*, 142.

⁵² Savitt, *Race and Medicine*, 42.

severe person rarely became symptom free.⁵³ Until the 1950s, it was believed a person with SCA can go from one group or stage.

Emmel's test was used to search for "Negro Blood" and ancestry which continued the racial thinking of eugenic racial origins and illness. Individuals characterized as "white" had SCA but for them the classification was different. Sickling for whites was not a matter of illness but a question of racial purity.⁵⁴ The consequence of being white with SCA was the stigma of being associated with "blackness;" socially outcaste and medically contagious. The stigma of "Negro Blood" permeated well into the mid-twentieth century. A June 1942 editorial by the New York Times called "Blood and Prejudice" reported the American Red Cross (ARC) segregated the blood donated by blacks and whites.⁵⁵ The American Red Cross' "Negro Blood" and "non-Negro Blood" policy, which ARC labeled bags of blood by racial distinction and separated them for transfusions.⁵⁶ Such eugenic blood ideology was counterproductive in the World War II era.

The notion of Jim Crow Medicine (separate but equal) in a time of war demolishes national solidarity and civic engagement. The white soldier died because "White Blood" ran out and he refused to receive "Negro Blood" or a black soldier could only receive "Negro Blood" without any other option. Emmel's test created an uncomfortable ambiguity to the external concept of racial identity. It awakened a society

⁵³ Savitt, *Race and Medicine*, 42.

⁵⁴ Tapper, Melbourne. *In the Blood: Sickle Cell Anemia and the Politics of Race*. Philadelphia: University of Pennsylvania Press, 1999. 16.

⁵⁵ Wailoo, *Drawing Blood*, 150.

⁵⁶ Wailoo, *Dying in the City of the Blues*, 89.

that the concept of race was not solely black and white. The variables are historical, geographical and literally skin deep at the cellular level.

Emmel's blood test of SCA complimented Mendelism to create racial identities and endorsed eugenics' role in society toward race and social policies. From the concepts of eugenics to Emmel's test, race was the crucial factor in disease discourse. Ironically, race did not construct medical science but medical science constructed race and social policies. In fact, the eugenic concepts of "Negro Blood" shaped insurance and social policies.⁵⁷ Medical science was the authority in shaping social policies in the early twentieth century, which maintained the status quo of race relations and developed the status of biological citizenship for African Americans with or without SCA.

Biological citizenship, termed by Dr. Adriana Petryna, is "the damaged biology of population has become the grounds for social membership and the basis for staking citizenship claims."⁵⁸ SCA created urgency for sanitary response by white support. Eugenic influence created a racial and biological caricature of African Americans with and without SCA. Individuals with SCA were called a derogatory term "sickler." As a result, biological citizenship for African Americans was a social and racial contagion, which created stigmas like criminality, poor moral virtue and contagiousness that expatriated African Americans through sterilization and its forms through population control, marriage control, and immigration policies.

⁵⁷ McBride, *From TB to AIDS*, 138.

⁵⁸ Pollock, Anne. *Medicating Race: Heart Disease and Durable Preoccupations with Difference*. Durham: Duke University Press, 2012, 40.

Sterilization

ERO's Superintendent Harry H. Laughlin was father of the eugenic sterilization and immigration policies in the early twentieth century. *Encyclopedia Britannica* describes sterilization as any process, physical or chemical, that destroys all forms of life, is used especially to destroy microorganisms, spores, and viruses. Sterilization was initially meant for the mentally ill or "feeble-minded" individuals. In 1897, Michigan state lawmakers considered to sterilize feeble-minded individuals by male castration and female ovariectomies through House Bill No. 672.⁵⁹ The Bill was introduced by Congressman and Physician W.R. Edgar but was opposed. In 1907, eugenics supporter US President Woodrow Wilson helped Indiana to adopt legislation making sterilization of "mediocre" or "undesirable" individuals legal.⁶⁰ Endorsed by state Representative Harry C. Sharp, Indiana's bill was the first state to legalize sterilization. Woodrow and Laughlin created a precedent of making sterilization a national priority to protect the progress of humanity by terminating "mongrel races." Indiana's law set the precedence of sterilization which became a national legal practice set in by the *Buck vs. Bell* case.

Carrie Buck was a seventeen year old woman who gave birth to a baby girl named Vivian. Buck's daughter was left in the care of her foster parents John and Alice Dobbs. Buck was characterized as feeble-minded and was sent to the Lynchburg State Colony for Epileptics and Feeble-minded. Buck's mother Emma was sent there in 1920. Dr. Albert Priddy was the superintendent of the Lynchburg State Colony. Priddy was a believer in sterilization of eugenically inferior people. He performed nearly a hundred sterilizations

⁵⁹ Largent, *Breeding Contempt*, 66.

⁶⁰ Sussman, *The Myth of Race*, 54.

of Virginian women in the 1910s.⁶¹ Priddy lobbied lawmakers of the Virginia state legislature and worked with endorser of the bill Aubrey Strode to pass the Eugenical Sterilization Act of 1924, which established the Lynchburg State Colony. Unsurprisingly, he wanted to sterilize Buck as a moral delinquent and feeble-minded (constitution of a nine year old) under the new state law.

In the case *Buck vs Priddy*, Priddy rationalized that sterilization would save Virginia money and would prevent Buck from future pregnancies. Laughlin's testimony was key in the law's approval. He testified:

All this is a typical picture of a low grade moron... The family history record and the individual case histories, if true, demonstrate the hereditary nature of the feeble-mindedness and moral delinquency described in Carrie Buck. She is therefore a potential parent of socially inadequate or defective offspring.⁶²

In 1924, the sterilization law was approved by the Virginia Supreme Court of Appeals but was appealed by Irving Whitehead (Buck's attorney). The original decision was upheld and went to the US Supreme Court in October 1926. Due to Priddy's untimely death in 1925, the case was changed to *Buck vs. Bell* in 1927 because Dr. J.H. Bell was Priddy's successor and the current Lynchburg State Colony superintendent.⁶³ The law stated Buck had due process of the law and equal protection under the law in an 8 to 1 decision. The law upheld eugenic laws passed by other states. *Buck vs. Bell* set the precedent of legal sterilization on a national platform, which enforced eugenic sterilization as a social therapeutic intervention to remove less desired groups.

⁶¹ Hansen, *Sterilized by the State*, 104.

⁶² Largent, *Breeding Contempt*, 100.

⁶³ Hansen, *Sterilized by the State*, 105.

Prior to World War I (WWI), African Americans were ironically spared from sterilization because of segregation. African Americans were not granted access to institutions that performed sterilization. That quickly changed after World War II (WWII). Post WWII African Americans became a target of the eugenic sterilization agenda. Sterilization was a form of race-specific therapeutic intervention to “cure” American society of inferior individuals who diminished human quality. This eugenic view was heightened through the passing of welfare laws in the 1930s.

Unemployment was a significant problem of the 1930s with 28% of households lacking employment.⁶⁴ Welfare and charity dependency dramatically increased, which led to the augmentation of pauperism. The results of unemployment created a eugenic epidemic with hordes of welfare dependents threatening the “genetically fit” of society. African Americans were the biggest group dependent on welfare by the unemployment hike. Welfare dependents became a public health crisis. In 1943, Lobbyist quickly formed the Sterilization League of New Jersey, which changed to Birthright Inc. Birthright evolved from Gosney’s Human Betterment Foundation to Human Betterment Association of America (HBAA). HBAA was the only national organization sponsoring sterilization.⁶⁵ After 1950, HBAA changed their agenda from coerced sterilization to voluntary sterilization. In 1962, HBAA became Human Betterment Association for Voluntary Sterilization and made its final name change in 1965 as the Association of Voluntary Sterilization (AVS).

⁶⁴ Hansen, *Sterilized by the State*, 238.

⁶⁵ *Ibid.*, 238-239.

African Americans with and without SCA were viewed as a social disease that should be prevented from procreating and should be eradicated from society. Welfare was used to justify sterilization of Blacks who were viewed as lazy, dirty, and diseased ridden. Such perceptions encouraged the creation of ghettos. Ghettoization is to put a specific group or groups in an isolated or segregated area. The belief that poor areas of classified inferior groups will cause and carry diseases will cause an epidemic threat to the eugenically superior of society. AVS linked sterilization with welfare. AVS' president H. Curtis Wood Jr. stated people on welfare were, "the cancer cells growing in an uncontrolled and destructive manner."⁶⁶ Furthermore, Wood asserted that welfare programs exacerbate poverty and the well-being of society. The first step to prevent African Americans to populate and "infect" was to limit procreation.

Eugenics notions influenced paranoia of African American reproduction started in the early twentieth century. For example, presiding justice of the *Buck vs. Bell* case, Justice Oliver Wendell Holmes Jr. stated, "Three generations of imbeciles are enough."⁶⁷ Emma, Carrie, and Vivian were viewed as feeble-minded individuals and were used to promote an example that feeble-mindedness passed down generationally. The US Supreme Court felt that feeble-mindedness was linked to promiscuity.⁶⁸ These ideologies were solely eugenic and were attributed to African Americans. African American sexuality was viewed as a threat that will replenish feeble-mindedness and compromise the procreative progression of an eugenically fit American society.

⁶⁶ Hansen, *Sterilized by the State*, 239.

⁶⁷ Largent, *Breeding Contempt*, 102.

⁶⁸ *Ibid.*, 101.

Chicago College of Physicians and Surgeons' Professor of Genito-Urinary Surgery and Syphilology, G. Frank Lydston was questioned about the sexual promiscuity and perversion of blacks by the American Medical Association president Hunter McGuire. McGuire wanted a scientific explanation of African Americans' perceived extreme sexual perversions. Lydston concluded, "Negro compares quite favorably as regards sexual impulses- taking all abnormalities into consideration- with the white race."⁶⁹ He believed African American sexuality was not the issue. Lydston's sexual views of African Americans were rare in his time. The general perceptions of African Americans sexuality were animalistic with insatiable sexual appetites. A view associated most often with black men. However, the only solution for stopping the spread of criminality and the deterioration of society by African Americans and those with SCA was through castration.

Lydston was not concerned with the sexuality of African Americans but with the eugenic threat they created through procreation. Lydston's *The Diseases of Society* influenced castration as a form of punishment and population control. "Therapeutics of Social Disease" chapter focused on solutions of criminology by two methods: controlling heredity through marriage selection and sterilization to improve environments by legislation. In "The Medical Aspects of Crime," castration was used as, "a possible and permissible mode of preventing the propagation of a degenerate class of imbeciles or paupers."⁷⁰ Simultaneously, castration was used as a form of punishment in rape cases and a means of aggressive population control to stop eugenically labeled inferior groups

⁶⁹ Largent, *Breeding Contempt*, 25-26.

⁷⁰ Ibid., 27.

from procreating. Castration was one form of eugenic population control. Another form was birth control.

Birth Control

Birth Control was developed and promoted by the founder of Planned Parenthood movement Margaret Sanger. Sanger was an avid eugenicist who stressed that those who are “genetically fit” should procreate and those who are “feeble-minded” and “mongrels” should be prevented from producing. She believed birth control and eugenics are connected ideas that cannot be separated. Her speech called “Plan for Peace” in the April 1923 publication *Birth Control Review* she wanted:

To apply a stern and rigid policy of sterilization and segregation to that grade of population whose progeny is already tainted or whose inheritance is such that objectionable traits may be transmitted to offspring and to give certain dysgenic groups in our population their choice of segregation or sterilization.⁷¹

Sanger along with other movers and shakers of the birth control movement like, Victoria Woodhull, Marie Stopes, Robert Dickinson, Lois Gosney-Castle, Paul Popenoe and Alan F. Guttmacher, influenced race-specific therapeutics through the eugenic practice of sterilization. The second form of eugenic population control targeted the institution of marriage and race relations.

Marriage Control

The Virginia Racial Integrity Act of 1924, influenced by the “One Drop Rule,” was the “first miscegenation law in the nation passed on a eugenic basis.”⁷² The law

⁷¹ Schrag, Peter. *Not Fit for Our Society: Nativism and Immigration*. Berkeley: University of California Press, 2010. 94.

⁷² Largent, *Breeding Contempt*, 65.

made lying about one's race in registry a felony with a punishment of one to five years in prison. The eugenic social policy of marriage was created by the threat of miscegenation (the interbreeding of different races) within marriage. Miscegenation became a national public health crisis because the transmission of blackness by African Americans and those with SCA and other diseases endangered the purity of the white race.

The Virginia law set a national precedent which influenced numerous states. Miscegenation was a national scare tactic that influenced immigration policies to take a eugenic turn. In a eugenic mindset, producing and marrying genetically inferior individuals and groups is not the only cause of social decay but allowing inferior groups to migrate is another threat to the American negative eugenic agenda.

Eugenicists believed that immigrants after 1890 were genetically undesirable.⁷³ Immigrants marrying and procreating was eugenically thought as reversing the country's progress. Laughlin has been working on immigration policy since 1920 with the US Congress and was a major influence in providing testimony and research for an immigration law to pass. Throughout the process of drafting immigration legislature, race-based and eugenics influenced the proposed immigration law's terminology. In 1924, the Johnson-Reed Immigration Act passed which provided a national origins quota system by only allowing two percent of the nationality's population with Asia being completely excluded. The Act was purposefully enforced to prevent individuals characterized as black to enter the country in fear of spreading SCA.

⁷³ Sussman, *The Myth of Race*, 100.

Linus Pauling

Sterilization through population control, marriage control, and immigration shaped African Americans' and SCA carriers' illness and identity. The results were scientific theorizing, clinical discovery, and political transformation. SCA became significant in the 1950s and 1960s because it served as the archetype that influenced the relevancy of molecular biology through post WWII medicine. Molecular biology of the mid-twentieth century was the equivalent and foundation of the Human Genome Project in the late twentieth century. The key player in molecular biology was Linus Pauling.

In 1948, the California Institute of Technology pioneered in the method of electrophoresis. Electrophoresis is the separation of molecules according to their electrical charge, which determined the difference between normal and sickled hemoglobin.⁷⁴ In 1949, the California Institute of Technology's Chemist, Linus Pauling published an article in the *Science* journal entitled "Sickle-Cell Anemia, A Molecular Disease," which explained individuals that carried SCA had a different electric charge compared to individuals who did not carry the disease. In the same year, sickle cell anemia was named the first molecular disease by Pauling. This was significant because it lead to the hypothesis that the cause of SCA maybe by an altered molecular structure and genes determined precisely the structure of proteins.

Pauling's characterization of sickle cell anemia classified the disease as a "black-race disorder" and suggested sickle cell was the consequence of a molecular mutation in the hemoglobin. As a result, Pauling inadvertently discovered race-based medicine. In

⁷⁴ Pauling, Linus., et al. *Linus Pauling: Scientist and Peacemaker*. Corvallis: Oregon State University Press, 2001, 129.

contrast, Emmel's test identified the characteristics of SCA. Pauling's discovery transformed SCA to another level and understanding of disease. The concepts of racial purity and disease were prevalent among American scientists who declared, "Sickle cell anemia in American blacks (who by definition, it was assumed, had white ancestry) was a perfect example of how race mixture can be disadvantageous in its racial effects."⁷⁵ Once again, SCA went from a proxy of race to a consequence of race.

Pauling and his scientists concluded sickle cell affected black Americans (hybrids) more than Africans (pure) who possessed the sickle cell trait. As a result of this conclusion, theories of racial admixture (the mixing of races through marriage, sex, and cohabitation) developed and advanced the idea that race can affect disease risk and severity. Pauling's finding earned him a Nobel Prize in Chemistry in 1954.⁷⁶ Pauling's influence in race, research, and medicine is reflected in the creation of the first race-based drug BiDil, which I will discuss more in chapter two. SCA was not the only inherited disease that had systematic racial influence in the late nineteenth and twentieth century. Eugenic influences affected Tay Sachs Disease and the Jewish population.

Tay Sachs Disease

Tay Sachs Disease (gangliosidoses or cerebral sphingolipidoses) is a rare inherited disorder that progressively destroys nerve cells (neurons) in the brain and spinal cord. TSD is a mutation affecting the development of the "Hex A" enzyme. The "Hex A" enzyme is an important function that controls the amount of fat in the nervous system and

⁷⁵ Fullwiley, Duana. "The Biological Construction of Race: 'Admixture' Technology and the New Genetic Medicine." *Social Studies of Science*. (Sage Publications, Ltd.). Oct2008, Vol. 38 Issue 5, 695.

⁷⁶ Pauling, *Linus Pauling*, 133.

the brain. When the enzyme is not working properly; excess fat accumulates resulting in neurological deterioration. Tay-Sachs is one of the most severe of childhood disorders.

TSD symptoms include hyperacusis (decreased sound tolerance “DST”), social withdrawal, mental retardation, cherry-red spots on the retinas, enlargement of the head due to the increase of water around the brain, and alteration in muscle tone. Eventually, the child becomes immobile, visually impaired, and dies by age four.⁷⁷ Similar to SCA, a person inherits TSD through Mendelian markers of abnormal/recessive genes one from each parent.

In 1881, TSD was first described by British ophthalmologist and surgeon Warren Tay. Tay’s observation of TSD led the British Ophthalmological Society to publish its first volume. After Tay’s first observation, he stated,

Mrs. L. brought her infant, 12 months of age, to see Tay at his office in London on March 7, 1881 “in the hope that something might be done to strengthen it” (1881:55). This baby was unable to hold “its” head up or move its limbs, and when asked about the baby’s eyesight, the mother replied “she did not think her baby took as much notice as other babies.”⁷⁸

Tay’s visual observations developed the precedent on TSD symptoms with Bernard Sachs to follow.

In 1887, Jewish Neurologist Bernard Sachs was one of America’s premier clinical neurologists. His first experience of TSD was when he saw brownish/cherry red spots in

⁷⁷ Reuter, “The Genuine Jewish,” 296.

⁷⁸ Ibid., 297.

a two year old girl's eyes. He classified TSD as "Amaurotic Family Idiocy,"⁷⁹ a mental and optical condition that was a hereditary trait. Sachs concluded,

Taking all these histories into account as they have been reported by a number of different observers, there can be no doubt that the cases described by the oculists [ophthalmologists] are identical with those seen by me, and they constitute a very definite family affection due to the occurrence of the affection in several members of the same family.⁸⁰

The disease ultimately was referred to as Tay Sachs named after Warren Tay and Bernard Sachs the discoverers of the disease. The validation of TSD's hereditary status made Jews vulnerable to the eugenic idea that race was a marker of disease.

TSD was generalized as a Jewish disease. In 1894, Dr. Curtis B. Carter labeled TSD as "a disease among the Hebrews" and in 1895 Sachs told the New York Neurological Society that TSD was a disease "almost exclusively Jewish."⁸¹ TSD was primarily from the Ashkenazis Jews from Eastern Europe. A development discovered in the 1930s. TSD was categorized as a sub group within the Jewish population. SCA was generalized as a black disease not considering the numerous back grounds from which those considered Black came. However, that did not stop the association of Jewishness and TSD. Before the turn of the twentieth century, eugenic bias purported that TSD was a contagious disease causing fear of pandemic. For example, Neurologist Dr. Isador H. Coriat alleged in one of his cases TSD nerve cells contained poison that was transmitted through Jewish mother's milk.⁸²

⁷⁹ Reuter, "The Genuine Jewish," 297.

⁸⁰ Ibid.

⁸¹ Ibid., 299.

⁸² Ibid., 298.

Furthermore, the danger of a Jewish mother breastfeeding was emphasized by Neurologist William Hirsch. In 1898, Hirsch observed a case which he asserted many children became infected with TSD by the same mother, which “obviously” explained why the family suffered from TSD. Hirsch encouraged stopping the practice of breast feeding suggesting, “That as soon as the diagnosis of such a case has been made, the child be taken from its mother’s breast, and all future children be fed with other nourishment.”⁸³ The perception of Jewish breastfeeding was believed to be a means of degeneration and threatened the well-being of the defined “genetically fit” society.

TSD, a mental and nervous disease, was categorized as a form of feeble-mindedness. Goddard through the Binet-Simon intelligence tests found that 60% of Jews were classified as morons.⁸⁴ The test consisted of various pictures and was meant for immigrants who did not speak English. The hierarchy of intelligence started with the “Nordic stocks” of Canadians, Scandinavians, British, Scottish, and Dutch. The lower stocks of intelligence were Jews, Polish (Poles), and Greeks with the Negro as the least intelligent. Princeton Psychologist Carl C. Brigham asserted, “The intellectual superiority of our Nordic group over Alpine, Mediterranean and Negro groups.”⁸⁵ Goddard and many eugenicists’ views on Jews and other races were influenced by a philosophy giant Immanuel Kant.

Kant viewed Jews (and other races like Blacks) as lesser human beings and described Judaism as a superstitious, dishonest, and a materialistic religion. In 2003, the United Jewish Appeal of Toronto states,

⁸³ Reuter, “The Genuine Jewish,” 298.

⁸⁴ Schrag, *Not Fit for Our Society*, 8.

⁸⁵ Ibid.

Going back to at least the twelfth century, European culture had developed a rich and ghastly tableau of imaginary Jews... Kant's division of humanity reiterated and reinvigorated the religious and racial hierarchies of the past... He took this earlier religious hostility toward Jews and reformulated it in philosophical language... Kant set the stage for modern secular anti-Semitism... [and] provided the framework for future anti-Semites.⁸⁶

Eugenic and Kantian influences inflamed the perception Jews are inferior. TSD classified Jewish people, whether they had the disease or not, as social outcasts. Russian Zionist Max Mandelstamm stated that Jews were a degenerate people, "that the decrepit, miserable, weak bodily constitution of the Jews of the ghetto is the exclusive result of their wretched social and economic situation."⁸⁷ Similar to African Americans, Jews were viewed as disease ridden people susceptible to numerous kinds of diseases. Jewish women were affected more by female related diseases compared to other women in other races. Negative TSD and other pathological connotations toward Jews created stigmas like the 'nervous' or "insane" Jew. Eugenic ideologies placed Jews within the social agendas of marriage, reproduction, and immigration policies tailored as race-specific cures of the Jewish problem.

Intermarriage Control

Jews were viewed as "Asiatic" and "oriental." Intermarriage was a huge concern because Jews would disrupt the racial purity of the Anglo-Saxon race. Founder of the eugenic organization The Northern League, Roger Pearson published a newspaper called *Northlander*. The newspaper was very influential in eugenic propaganda about how the

⁸⁶ Sussman, *The Myth of Race*, 29.

⁸⁷ Hart, Mitchell B. "ARTICLES - Racial Science, Social Science, and the Politics of Jewish Assimilation." *Isis*. 90.2 (1999), 276.

Aryan race created civilization, Nordic supremacy, and the threats of miscegenation.⁸⁸

TSD and the views of intermarriage was one of the main agendas of eugenic propaganda.

Eugenics influenced the Father of Zionist Movement and Social Scientist Arthur Ruppin. Zionism, a political movement aimed at creating a Jewish homeland in Israel. He believed Jewish intermarriage produced negative racial consequences. Zionists' nation state is not based on religion but by national identity. Ruppin believed intermarriage would dramatically alter the physical, cultural and spiritual distinctions of Jewishness. In the 1904 *The Jews of Today* publishing, Ruppin stated Jews,

Whose facial physiognomy displays none of the traits of the so-called Jewish type, whose morphological type cannot be identified as of Jewish descent is substantial. Therewith the last bridge, racial unity, connecting eastern and western Jewry, divided as they are already culturally, will be destroyed. And since their bond with eastern European Jewry has vanished and they stand alone, the absorption of western European Jewry will happen quite easily.⁸⁹

Ruppin's idea of intermarriage created an interesting binary. First, intermarriage was disliked in a Jewish Zionist perspective because it threatened one's identity. Second, intermarriage was disliked in an American eugenic perspective because TSD compromised the eugenic ideal of racial purity. Both concepts embraced and justified racial identity and exclusivism. Ruppin viewed intermarriage as a schism that will cause a fragmentation of Judaism.

America's framework has always produced a heterogeneous society. Eugenics promoted an "us and them" narcissistic mentality of constructed racial pride. An important sense of racial pride was the sense of reproduction, which brought hope for a

⁸⁸ Sussman, *The Myth of Race*, 242.

⁸⁹ Hart, "Racial Science," 278.

socially fit future. Since TSD was a children's disease, the fear of a generation gap and social inadequacy intensified. Eugenicist and professor of Neurology at Tufts College Medical School Abraham Myerson believed insanity and feeble-mindedness were traits of TSD. In 1925, Myerson published *The Inheritance of Mental Diseases* which he suggested epilepsy has many pathological origins in its nature.⁹⁰ In 1933, Davenport's newspaper *Eugenical News* commended Germany on their eugenics movement, by publishing eugenic journals like the *Archiv für Rassen- und Gesellschaftsbiologie* (Archive for race and society biology).⁹¹ In 1936, Germany awarded Laughlin an honorary doctor of medicine.

In 1935, in the *Archives of Neurology and Psychiatry*, Myerson published "A Critique of Proposed 'Ideal' Sterilization Legislation" powerfully illustrating against mass sterilization but hypocritically justified the sterilization of Communists, Capitalists, and Jews. *Buck vs. Bell* was indirectly used by Myerson to justify abortions of Jewish babies due to TSD. Myerson felt Jews were, "those restless and reckless persons who fail because they attempt too much, but who care the ferment by which the mass is lifted."⁹² Myerson's "mass" was the burden of perceived inferior individuals like the Jews. Sterilization through reproduction was the solution to prevent the spread of TSD. At the time, the eugenic use of intermarriage and reproductive restrictions supposedly protected the social elect. However, the most influential policy to prevent the "infiltration" of Jews to America was immigration.

⁹⁰ Largent, *Breeding Contempt*, 98.

⁹¹ Washington, *Medical Apartheid*, 193-194.

⁹² Largent, *Breeding Contempt*, 99.

Immigration

The industrial Revolution was connected with immigration, menial and unskilled jobs which also defined the Jews “not-quite-white” status. Racial biology created classifications that formed social boundaries and segregated American citizens. Jews (including Irish, Polish, and Italians) were the different type of whites mining and manufacturing workers socially placed in the lower class while making white owners of industrial empires wealthy.⁹³ The classism of labor classified industrial owners as the “genetically fit” and the labor workers as the “unfit” connecting business practice with Darwinism. Whiteness was not solely skin deep but was a reflection of economics, power, political and social means starting from the middle class; an idea that hindered Jews from the classification and attribution of “Whiteness” until mid-twentieth century.

Immigrants were viewed as the enemy and often blamed for deflating wages, abusing public assistance, and as a public health threat. For example, in 1892, typhus and cholera infected New York City. New immigrants were detained and placed in quarantine station off Staten Island.⁹⁴ Nationalism (citizens identifying with one's nation) was replaced by nativism (protecting the interests of native-born or established inhabitants against immigrants). Being an American took on a different meaning depending who you were. The American “melting pot metaphor” promoting diversity and unity was a far cry from eugenic ideology. Only certain groups were considered to be accepted into the melting pot. Other groups like African Americans and Jews were considered to be the fire to help stir the pot but by no means considered the movers and shakers of America.

⁹³ Brodtkin, Karen. *How Jews Became White Folks and What That Says About Race in America*. New Brunswick, N.J.: Rutgers University Press, 1998, 55.

⁹⁴ Reuter, “The Genuine Jewish Type,” 306.

Jews left Eastern Europe to start a new life free from anti-Semitism that led to genocide and persecution. Unfortunately, Jews did not escape social constructions that questioned their humanity and worth. American society viewed Jews as an inbreeding and racially incestuous type of people; qualities not viewed as American. Eugenic influence in immigration used TSD as a proxy for racial ideological purposes, much like SCA that was associated with African Americans. Eugenic thought vehemently imposed ideologies that Jewish assimilation into American society did not improve social and public health. Viennese physician Martin Engländer endorsed the link between Jewish assimilation and degeneration. He stated, “The startling frequency of illness among the Jewish race.”⁹⁵ Engländer claimed in his 1902 study there was a connection between middle-class western European Jews statistics and higher rates of alcoholism, mental and nervous disorders, and suicide. Physician Hugo Hoppe cited statistics similar to Engländer with criminality as a trait among assimilated Jews.

The Jewish “parasite” and “germ” were powerful anti-Semitic imagery and designations that permeated within the American perception of Jews. Negative racial Jewish perceptions Alan Kraut states,

sought to sketch the Jew as a public health menace, one who might end up on the public relief roles in droves, deficient in the physical vitality to stand the test of the rugged American environment, as did the pioneer forbearers of the native-born and the sturdier stock that had emigrated to the United States from Northern and Western Europe.⁹⁶

Jews were viewed to be fickle individuals that cannot physically handle the burden of assimilation compared to African Americans who were viewed by brutish and

⁹⁵ Hart, “Racial Science,” 278.

⁹⁶ Ibid., 285.

primal perceptions. US Navy Medical Director Dr. Manly H. Simons acknowledged immigrant Jews' "increasing degradation, retardation, and extinction to an inability to adapt their genetic constitution to their new circumstances."⁹⁷ Simons, influenced by the Mendelian technique, noted family disease like TSD lead to early death or sterility. These assumptions were based on alleged and repeated hereditary racial qualities in Jews.

There was a continued fear that degeneration would wipe out white American civilization. Racial and medical discourse of TSD and SCA was bound with ideological views on immigration and race. Doctors and other medical professionals became instigators who ingrained their research, study, and medical voice with eugenic and nativist discourse. These individuals became medical antagonists constructing an issue that was mainly social and made it a biological one that threatened the well-being of American society. Hence, immigration was a race-specific cure or a "social antibiotic" that would lessen the diseased Jewish presence in America.

Officer of the American Eugenics Society and vice-president of the Immigration Restriction League, Madison Grant asserted that immigration would degrade America's Nordic racial constitution. He believed, "the man of old stock is being crowded out of many country districts by these foreigners just as he is to-day being literally driven off the streets of New York City by the swarms of Polish Jews."⁹⁸ New York University Professor of Sociology Henry Pratt Fairchild, TSD as an "Excludable Medical Condition" according to the American Book of Instructions for the Medical Inspection of Immigrants

⁹⁷ Reuter, "The Genuine Jewish Type," 308.

⁹⁸ Ibid.

who indicates that mental defectiveness, among other conditions, is also “excluded by the immigration law.”⁹⁹

The same ideology was embraced by German-Jewish anthropologist Franz Boas. Boas primary research was on the anatomy of Jewish immigrants. His earliest studies were the head forms of Jews. Boas studies were an assimilationist example of physical anthropology, which had a major influence on immigration policy. In the 1903 journal *American Anthropologist*, he published “Heredity in Headform.” The article examined the relationship between inheritance and head forms comparing it to Mendel’s research and hypothesis. Boas’ article had case studies of forty-nine Jewish families organized by Maurice Fishberg.

Maurice Fishberg was a New York physician and anthropologist. Fishberg’s research had great influence on Boas. For example, Boas’ article on “Race, Immigration, and Assimilation, Changes in Bodily Form of Descendants of Immigrants,” was heavily influenced by Fishberg’s studies. Boas article was a key source in the 1911 forty volume study of the U.S. Congress Immigration. The study “symbolized the high point of political propaganda for immigration restriction before the immigration laws were enacted in the twenties. The investigation should be directed towards an inquiry into 1) the assimilation or stability of type, and 2) changes in the characteristics of the development of the individual.”¹⁰⁰

TSD cases reported prior to the 1924 Johnson-Reed Immigration Act contained racist and nativist language, associating Jews to nervous diseases like TSD due to their

⁹⁹ Reuter, “The Genuine Jewish Type,” 309.

¹⁰⁰ Hart, “Racial Science,” 287.

racial inferiority. From 1913 to 1918, Physician Isador Coriat asserted, “[e]ven if the parents are apparently healthy, they have probably inherited a nervous disposition from their persecuted and maltreated ancestors. The Jew possesses certain racial characteristics of organic inferiority through which he differs from the non- Jew.”¹⁰¹

The 1924 Johnson-Reed Immigration Act was influenced by eugenicists like Fishberg, Boas, and Laughlin. The only way to prevent minimal social reaction was to frame a structure of encapsulation among Jews, which the ghetto concept was used as a solution. Homogenous neighborhoods were a eugenic justification for racist and biased real estate and mortgage practices. The premise was that immigration could not keep every undesirable group of people out of the country. The idea of putting the same “type” of people in a specific location to maintain homogeneity; such action will prevent intermarriage, reproductive issues and protect the socially fit.

The Eugenics Movement influenced race-based social policies viewed as therapeutic interventions (cures) to prevent an American infection of African Americans and Jews with and without SCA and TSD. The classifications of SCA as “a black disease” and TSD as “a Jewish disease” constructed false perceptions of tailored research and technology for specific racial groups, which made race a proxy in medicine. In chapter two, I will examine misunderstandings, perceptions, experimentations, consequences, and African Americans’ response relating to the race-based medicine and the black body

¹⁰¹ Reuter, “The Genuine Jewish Type,” 310.

Chapter 2

RACE-BASED MEDICINE: MALEFICENCE TOWARD THE MINORITY PATIENT

The idea of race-based medicine creates maleficence (harm) in minority patient care. Eugenic influence created false assumptions and stereotypes (the homogeneity of characteristics, experience, and behavior of a group and individuals from that group) about the black patient's body. Physicians' infatuation of the black body created a disturbing language, which caused unconscionable harm in the clinical practice. Inaccurate semantics and perceptions provided the justification of inhumane experimentations on black bodies. Racial history utters the eerie weight of race and biology illustrating racial stereotypes that disrupt clinical judgment and induce unconscious bias. As a result, deeply rooted mistrust remains at the core of African Americans and their participation in the clinical process. This chapter will examine the maleficence of minority patients through the misappropriations of the black body, race-based experimentations, consequences of misappropriations about the black body and African Americans' response to race-based experimentation.

Misappropriations of the Black Body

As discussed in chapter one, the historical usage of race in medicine and research has deteriorated the human worth of communities of color and lead to genetic and biological propaganda. For over 400 years, the human development of race has not promoted ethical engagement, solidarity, and literacy but has been used to oppress, exclude, and dehumanize individuals and groups. Human history has demonstrated the use of race has substituted prudence and practical wisdom for antagonistic and apathic

treatment toward black human beings. For example, the physical stereotypes of African Americans.

The eugenic perceptions, of the “black body,” produced misappropriations and falsified theories of the anatomy and biology of black individuals. Darwinism and human variation studies have formed ideologies that black individuals are subhuman, and that their physiological attributes are similar to apes.¹⁰² It also justified the concept of racial hierarchy, which asserted one’s race is superior compared to other races. Such beliefs challenged the personhood of African Americans.

Personhood

The era of slavery and the eugenics movement altered the personhood of African Americans. The auction block of slavery shaped the experience that black bodies have been a public spectacle with law and medicine defining the black body’s worth and aesthetics. The stain of anti-black body discourse still remained in American society. African Americans had the unique experience of surrogacy having their private faculties of their bodies but no bodily ownership.

Such oddity of bodily experience was evident in the terrorism of lynching in the late nineteenth century and early twentieth century, the Jim Crow era’s separate but equal legality, punishment against the status quo in the Civil Rights era, and excessive physical force between the police and communities of color. The physical degradation and death of black bodies rarely if ever receive justice or accountability. One reason is the notion of privacy. As Dr. Karla FC Halloway suggests, “Privacy is presumed to be a fundamental

¹⁰² Hoberman, *Darwin's Athletes*, 150.

right of personhood.”¹⁰³ Privacy and vulnerability are linked together. If you can take away someone’s privacy and vulnerability you can take away their personhood.

Citizenship gives privacy along with status, rights, privileges, and responsibilities that are contrary to a non-citizen. Thus, American history made black bodies private entities in public discourse.¹⁰⁴ Black bodies had value and identity according to public assignment and association by law and medicine which affected the autonomy of the black body.

Autonomy, in the Greek, means *autos* (self) *nomos* (rule, governance, or law).¹⁰⁵

Individual autonomy is free of controlling agents and limitations. Autonomy gives one the freedom and capacity to have self-rule and perform intentional actions. Autonomy is important because what controls a person controls their destiny. If one cannot control their own destiny, that individual is simply a pawn with no liberty to adequately thrive and express oneself. Liberty and agency are the principals of personhood without them no individual can attain their full potential. As Dr. Holloway mentions,

A critical distinction lies in what Rubenfeld explains as the juxtaposition of a (human) person’s claim to self-identity and the (social) person’s acknowledgment of the interior (private) and exterior (public) locations of self. Liberty cannot be a claim of individuality when individual identity is filtered through our associations or assignments to identity categories. Similarly, mirroring the way that an individual cannot liberate herself from the communitarian claims of social personhood, social, political and legal citizenships have assigned a differential ethical value to particular kinds of citizens at different moments in our history.¹⁰⁶

¹⁰³ Holloway, Karla F. C. *Private Bodies, Public Texts: Race, Gender, and a Cultural Bioethics*. Durham, NC: Duke University Press, 2011, 9.

¹⁰⁴ *Ibid.*, 18.

¹⁰⁵ Beauchamp, Tom and James Childress. *Principles of Biomedical Ethics*. Oxford: Oxford University Press 6th Ed; 2008, 99.

¹⁰⁶ Holloway, *Private Bodies, Public Texts*, 20.

An individual or a group with assigned identities and diminished autonomy, controlled by social systems, laws, and those of influence, cannot adequately act on their desires and plans.

The black body's autonomy has been compromised by its regulation and misappropriation. Western society rooted in xenophobic systems continues the systematic discourse of sustaining the inferiority of black bodies to continue to keep such individuals "in their place" and hinder any kind of autonomous action. African American bodies are disrespected for their autonomy because of Western ideas, actions, and attitudes that "ignore, insult, demean, or are inattentive to others' rights of autonomous action."¹⁰⁷ As a result, black bodies never were valued and respected, which sustains challenges of self-worth and self-esteem that continue to exist in the black community.

The inconsideration of the black body's autonomy jeopardizes the other three fundamental principles of biomedical ethics: non-maleficence (doing no harm), beneficence (doing good), and justice (what is deserved). When the black body's autonomy is devalued non-maleficence, beneficence, and justice cannot be accomplished. Furthermore, the black body being hindered from autonomy leaves it in a dependent discourse of stereotypes and preconceptions that takes away self-identification.¹⁰⁸ The ideologies of African Americans being "lesser than" or "inferior" transferred into the fields of anthropology, anatomy, and biology creating myths of innate human differences.

¹⁰⁷ Beauchamp, et al., *Principles of Biomedical Ethics*, 103.

¹⁰⁸ Such examples happened to sports legends Jesse Owens and Jackie Robinson. Owens and Robinson are among the first black professional athletes to be typecasted, scrutinized, and medically examined due to their athletic abilities. The "extra tendon" in black athletes' legs or sensitive heel that makes them jump higher or run faster than normal, are physiological misconceptions that still exist in our society. Owens and Robinson are examples of how American Society viewed African Americans as "the other" type of personhood.

Pseudo-Biology

American medicine and research influenced the perverse overreaction to African Americans' physiological and anatomical traits which produced unsettling claims that portray blacks as extra-terrestrial beings. In categorical order, the black body was viewed as abnormal. The misappropriations of blacks were the physiological judgements comparing perceived innate biological differences between blacks and whites.

A well-known racist southern physician, Samuel Cartwright was influential assigning alien attributions to the black body. He asserted the black body was different than the white body in every way. Cartwright said,

It is not only in the skin that a difference of color exists between the negro and the white man, but in the membranes, the muscles, the tendons, and in all the fluids and secretions. Even the negro brain and nerves, the chyle and all the humors, are tintured with a shade of the pervading darkness. His bile is of a deeper color, and his blood is blacker than the white man's.¹⁰⁹

Every physician did not agree with Cartwright's ideas of the black body but such ideas fueled racist perceptions of blacks. The pseudo-biological addiction of the black body created systematic descriptions that led to the black pandiculation of normativity to mythology.

The understanding that black bodies were innately different produced the terms "black hardness" and "black durability." These are the notions that African Americans have the innate capacity to endure or tolerate extreme conditions or illnesses. It was thought the experience of slavery made African Americans evolve to be a people of great endurance and stamina. Such ideas were used as an explanation of how blacks survived

¹⁰⁹ Hoberman, *Darwin's Athletes*, 147.

the sin of slavery. The black body had to be abnormal because the humanity of a white body did not have the capacity to endure what black bodies experienced. Cartwright associated black hardness with the physiognomy of blacks. Cartwright stated, “Black skin, thick lips, flat nose- corresponded to an intensification of vitality and physical strength.”¹¹⁰ It was also believed that African Americans did not get eating disorders due to their “gastric hardness.”¹¹¹ The durability of the skull and skeleton of blacks were popular among anthropologists.

The skulls of African Americans were deemed to be smaller than whites concluding that the black brain was not as developed as whites. As a result, blacks cannot reach the same intellectual capacity of whites. The notion was puberty was the start black people skulls started to rapidly thicken, and “the animal portion of the brain then became supreme, ruling over the adult Negro organism.”¹¹² The “animal portion” of the African Americans brain allegedly hindered social mobility, intellectual and social progress. Therefore, blacks were stuck in the same primitive state since their inception.

In 1859, German anthropologist Theodor Waitz said black skulls were so thick that one use is in fighting. Waitz said, “Negroes, men and women, butt each other like rams without exhibiting much sensibility.”¹¹³ Also, he believed that the black skeleton is heavier, thicker and larger compared to a European. Waitz’s colleague anthropologist Carl Vogt agreed that blacks use their skulls to fight similar to rams. In 1860, a woman novelist stated that it is physically impossible to knock a slave out down to the ground

¹¹⁰ Hoberman, *Darwin’s Athletes*, 213.

¹¹¹ *Ibid.*, 185.

¹¹² Nolen, Claude H. *The Negro's Image in the South; The Anatomy of White Supremacy*. Lexington: University of Kentucky Press, 1967, 3.

¹¹³ Hoberman, *Darwin’s Athletes*, 188.

because black skulls were so thick that the skull would bruise or break the slave-owner's hand.¹¹⁴ The next black features viewed differently were the eyes, ears and legs.

The eyesight and hearing of blacks were thought to be super human and extremely sensitive in various environments. Samuel Cartwright asserted, "The negro's hearing is better. His sight stronger and he seldom needs spectacles."¹¹⁵ The legs of blacks were thought to be different from the hormonal theory or gland theory of racial difference proposed by British anthropologist Arthur Keith. Keith's rationale was the dissimilarities of whites and blacks were caused by the functioning of endocrine glands. Keith concluded, "The long 'storklike legs' of some Negroid types have been thought by some to be due to abeyance of interstitial gland action."¹¹⁶ The glands of blacks had to be different because it explained the physical advantages blacks possessed compared to whites. Blacks' longer limbs and shorter trunks was the reason why blacks could run faster than any group. In 1964, Anthropologist J.M. Tanner continued belief that black bodies are different. He suggested that African Americans had longer arms and legs, heavier bones, narrower hips, and shorter trunks compared to whites.¹¹⁷

Even the joints, body fat, and muscle fibers of blacks were believed to have peculiarity. Blacks (particularly black athletes) were double-jointed, which allowed hyper-extensibility an idea claimed by anthropologist Edward E. Hunt Jr.¹¹⁸ Blacks has less body fat than whites, which contributed to their physical advantage. In the 1964

¹¹⁴ Hoberman, *Darwin's Athletes*, 176.

¹¹⁵ Ibid., 153.

¹¹⁶ Ibid., 158.

¹¹⁷ Ibid., 196.

¹¹⁸ Ibid., 200.

Tokyo Olympics, James E. Counsilman of Indiana University believed that black athletes had more muscle fibers. Mr. Counsilman said,

I believe that the black athlete has more white muscle fibers. Oversimplifying it, every muscle has two types of fibers – white fibers and red fibers. The white muscle fibers are adapted for speed of movement, otherwise power. The red muscle fibers are adapted for endurance... I think the difference in muscle fibers is the reason the black athlete is a better sprinter.¹¹⁹

Racial differences did not end with comparing the physiology of black and whites. The discourse continued with constructing pathological difference among races.

The *Southern Medical Journal* (SMJ) was a key contributor in influencing medical myths about the black body. In 1934, SMJ indicates,

Syphilis behaves differently in the white and the negro, and attacks the various organs and systems of the body with different force. One can only wonder how much of the negro's reaction to disease is different from the Caucasian because of *native endowments, structural and functional*. That the negro has *anatomical peculiarities*, is prone to certain diseases and relatively free of others is recognized (*Emphasis Added*).¹²⁰

It was the language of medical journals like *SMJ* that made race a proxy for pathology.

Since blacks and whites were viewed as opposite types of beings, physicians believed that black and white illnesses happened seasonally. The Association of American Anatomists was very assertive to “keep a careful record of all variations and anomalies between whites and blacks.”¹²¹ It was believed that blacks' vulnerability to become sick was in the winter and spring and whites became sick in the summer and autumn. There were even inquiries if antibiotic therapy had different reactions between

¹¹⁹ Hoberman, *Darwin's Athletes*, 194.

¹²⁰ Ibid., 149.

¹²¹ Ibid., 148.

blacks and whites.¹²² Heat was another factor that affected the illnesses of blacks and whites.

The notion of “heat tolerance” is the belief that blacks innately can endure high temperatures compared to whites. This was the general view among slaveholders. Black slaves were in the heat all day without any perceived physical deterioration. Inquiries of whether blacks’ sweat was different emerged because it had an intense smell. Cartwright believed that blacks’ heat tolerance was an “ethical peculiarity in harmony with their efficiency as laborers in hot, damp, close, suffocating atmospheres- where instead of suffering and dying, as the white man would, they are healthier, happier and more prolific than in their native Africa.”¹²³ The main trait that was believed to aid blacks in the sun was their skin.

Black skin was the essential symbol of hardiness. It was the symbol that superseded all other black characteristics that perceived blacks to be inferior. Black skin was viewed as thick and tough. Its alleged thickness was “credited with an increase resistance to both infection and diseases such as scarlet fever, erysipelas, and measles.”¹²⁴ Even in the late twentieth century, it was believed that black skin decreased the number and penetration of mosquito bites. The South Carolina physician, C.W. Kollock suggested,

The black man’s skin, the most obvious mark of inferiority, was believed to possess certain peculiar qualities other than distinctiveness of color. It secreted oil which kept it in a state of shine, thus deflecting intense solar rays. The pigment carried heat into the system, there driving water to the surface, which in evaporation dissipated body heat. The negro made an excellent worker because he

¹²² Hoberman, *Darwin’s Athletes*, 150.

¹²³ *Ibid.*, 152-153.

¹²⁴ *Ibid.*, 174.

was eminently a sweating animal; but this remarkable sweating capacity, however is useful in the field, caused him to be a pariah in white society, objectionable in the jury box, the legislature, or the drawing room. During Radical Reconstruction the 'sweetness of loyalty perfumed the air' of legislature and political meeting, and white men held their noses.¹²⁵

As discussed, the skin and other traits of African Americans were used to sustain the black hardiness theory. The binary of super-human and sub-human applications of the black body were complex and contradictory. The hardiness of blacks can be misinterpreted as positive traits but such descriptions were viewed as primal and inferior. Black hardiness and blacks perceived human inferiority was a means to justify suffering and exploitation.

The assumed durability of blacks constructed the ideology of "the pain-resistant Negro." Blacks' thick skin and sensitive nervous system made them endure whippings without feeling pain.¹²⁶ Black women did not feel pain in child birth. It was viewed African Americans were best in surgery, because "they are stoic in their reaction to pain and discomfiture, do not easily go into shock, take anesthesia well, resist infection, and show remarkable powers of recovery."¹²⁷ Even heart surgery and glaucoma physicians felt did not cause African Americans pain. A 1932 and 1952 physician's report stated that two black patients, one who had surgery and another who lost eyesight, handled pain and symptoms extremely well and did not use treatment until pain was a factor.¹²⁸

The myth of the black body and its defiance to pain created the perception that African Americans were mystical and black bodies possessed magical powers. Black skin was believed to have special healing powers, a black person saliva cured thrush, and

¹²⁵ Nolen, *The Negro's Image in the South*, 5.

¹²⁶ Hoberman, *Darwin's Athletes*, 176.

¹²⁷ Ibid., 177.

¹²⁸ Ibid., 183.

Appalachian folk medicine believed the spit of a very dark skinned black with “blue gums” can cure ringworm.¹²⁹ Such ideas of black hardiness and mysticism influenced and transferred into clinical research.

Race-based Experimentation

Race-based experimentation was the American medicine community’s response to the misappropriations of the black body. Experimentation on blacks started from the slave era. Slave owners and physicians developed ideologies and procedures that set the unethical precedence of the clinical process for African Americans. Unethical treatment of blacks continued through the military, which elected blacks to harmful clinical projects. This same treatment continued within prison systems. The “uniqueness” of the African American body constructed by racial biology justified the need for the harmful clinical experiments and led to two binaries of clinical research.

First, the black body (and other races) needed to be examined in order to understand specific race anomalies, disorders, and illnesses. Through the sustained notion of black hardiness, the first binary sustained maleficence to black bodies and disrupted autonomy of black patients by the physical afflictions experiments left on the body. Second, the black body was used in the expansion of knowledge in anatomy, pathology, epidemiology, disability, and physiological reactions to certain drugs and substances.

These two binaries created as Michel Foucault coined the “clinical gaze” or the “medical gaze.” In Dr. Cynthia Davis’ book *Bodily and Narrative Forms: The Influence*

¹²⁹ Covey, *African American Slave Medicine*, 44-45.

of *Medicine on American Literature*,¹³⁰ 1845-1915, she mentions Foucault's definition of the term,

The clinical gaze is a gaze of the concrete sensibility, a gaze that travels from body to body as a simple unconceptualized confrontation of a gaze, a face, or a glance and a silent body. The empirical and non-reciprocal nature of such confrontations depends upon the medical eye remaining both the depository and source of clarity were it would be clouded by doubt, by emotions, its clinical authority would risk being undermined, subjecting the clinician to the sort of scrutiny he sought to employ with others and avert from himself.¹³¹

The “looking down” and “looking over” black human beings value created the self-inverted gaze as whites being spectators and participants in clinical racial scopophilia.¹³²

“Clinical Trial” is a term used in the twentieth century in the competitive area of research and science. Clinical comes from the twentieth century expansion of the word clinic with clinical meaning “coldly detached.”¹³³ It replaced the taboo term “medical experiment.” In Latin, experiment means *ex* (from or out of) and *periculum* (a dangerous trial).¹³⁴ A clinical trial can be used for therapeutic and non-therapeutic purposes.

Curiosity, human detachment, combined with the black hardness ideology, led to the

¹³⁰ Dr. Davis' book explores resistance to scientific hegemony in nineteenth-century literature. She explains medical and scientific constructions of embodied identity were assigned to African Americans. Dr. Davis' work contributes to the conversation of how American medicine and medical literature sustains oppressive perceptions of black bodies.

¹³¹ Davis, Cynthia J. *Bodily and Narrative Forms: The Influence of Medicine on American Literature, 1845-1915*. Stanford, Calif: Stanford University Press, 2000, 14.

¹³² Jackson, Ronald L. *Scripting the Black Masculine Body Identity, Discourse, and Racial Politics in Popular Media*. Albany: State University of New York Press, 2006, 18.

¹³³ Holloway, *Private Bodies, Public Texts*, 114.

¹³⁴ Washington, Harriet A. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. New York: Doubleday, 2006, 55.

desensitization of harming black bodies in American medical experimentation.¹³⁵ Such experimental processes started during the slave era.

Slave Experimentation

The areas where slaves lived on the plantation were called the slave quarters. It was in such locations where most of the clinical work on slaves were done. Slave quarters were known as “Slave Hospitals” or “Clinic Wards.”¹³⁶ Since the belief of race held a strong assertion of biological difference, different treatment of blacks made sense because one was dealing with a different type of body and personhood. It was in the slave hospitals where American medical experimentation founded its origin.

Slave Owners and physicians had a mutual level of understanding in regards to slaves in the clinical process. A lot of physicians were slave owners themselves, which brought familiarity with handling sick slaves. It was the slave owner who gave or declined consent and responded in favor or disapproval to the physician. Slaves were not considered patients and deemed medically incompetent. Informed consent was ambiguous and often information was withheld if it complicated the medical process or left the slave paranoid.¹³⁷ However, there were rare occurrences of dual consent in the process of consent between the slave owner, physician, and slave.

¹³⁵ The most notorious examples of clinical or medical experimentation and treatment of African Americans were the Tuskegee Study of Untreated Syphilis in the Negro Male (also known as the Tuskegee Experiment) and Henrietta Lacks’ cervical cancer tumor cells called “HeLa cells” being used for research and monetary gains. In both cases, black subjects were not given informed consent (an individual’s autonomous authorization of a medical intervention or of participation of research) and were taken advantage of due to their socioeconomic status. The Tuskegee Experiment and Henrietta Lacks cases are examples of many abuses on the black body and are not the only cases of unethical treatment of minorities.

¹³⁶ Washington, *Medical Apartheid*, 57.

¹³⁷ Fett, *Working Cures*, 145.

Professor at Savannah Medical College, Dr. Juriah Harriss wanted to remove tumors from an enslaved woman's ears. Assuming that the tumors were no danger to the slave, the slave owner honored the slave woman's request.¹³⁸ Another example, Virginian surgeon Dr. Charles Bell Gibson was discerning his next move in a hernia operation of a slave man. The slave had an undescended testicle during the hernia surgery. Gibson decided not to remove the testicle because, "I had no right to castrate a man without his consent, or that of his master, prevailed against the temptation to lop off this misplaced testis."¹³⁹ Such form of graciousness should not be confused with the core of these decisions. The production of the slave is the most important result of these surgeries. Overall, slaves did not have ownership of their bodies, which made slaves vulnerable to surgical procedures and experimentations that caused them harm.

The third President of the United States of America Thomas Jefferson was a slave owner and fathered slaves. He was very interested in the field of medicine and often used his slaves as physical specimens for his clinical research. Specifically, Jefferson injected his slaves through vaccination experiments.¹⁴⁰ He was interested about the inoculation or variolation technique. In 1796, Dr. Edward Jenner created this technique injecting cowpox (disease of cattle) to establish immunity to smallpox. Hence, the inoculation process was injecting infected material from a sick person directly into a healthy person to induce immunity. Jenner discovered the localized and benign disease of cowpox when

¹³⁸ Fett, *Working Cures*, 146.

¹³⁹ Ibid.

¹⁴⁰ Washington, *Medical Apartheid*, 59.

the disease was transmitted from the cow to human hands.¹⁴¹ Jefferson used this technique on a slave who survived the inoculation process.

In 1832, the typhoid fever epidemic swept through Virginia. The epidemic was thought to prevent slaves from working and getting whites sick. There was no cure for typhoid fever. Dr. Robert G. Jennings used the inoculation process on thirty slave and free blacks using the smallpox vaccine and withheld the vaccine from others. Jennings reported that his experiment worked.¹⁴² Ironically, the smallpox vaccine is not efficacious against typhoid fever but in Jenner's case miraculously worked. There has been no duplication and explanation on Jennings experiment, which remains a medical mystery. Black slaves contributed to the acceptance of vaccination, in American medicine, through Jenner's technique without any considered agency and consent.

Individuals classified as poor were used in experimentation. However, slaves' bodies were used to continue clinical curiosity on how disease and illness works. Black bodies were disproportionately used more compared to other groups. Blacks had no legal protection on medical experimentation and no citizenship. Therefore, there were no consequences if a slave was abused or even killed for medical purposes. In the nineteenth and twentieth centuries the black body was a figurine for medical research. For example in 1836, half of the articles in the *Southern Medical and Surgery Journal* were on black bodies. Second example, Optometrist Dr. James Dugas used 80% of black slaves as

¹⁴¹ Savitt, Todd Lee. *Medicine and Slavery: The Diseases and Health Care of Blacks in Antebellum Virginia*. Urbana: University of Illinois Press, 1978, 294.

¹⁴² Washington, *Medical Apartheid*, 60.

subjects in his pioneering eye technique. Lastly, slaves were used in genitourinary and bladder stone surgeries.¹⁴³

The experimental usage of slave bodies was encouraged by the continued language by physicians that blacks did not feel pain or anxiety. Physicians like Dr. Charles White and Dr. James Johnson continued the discourse of black hardiness in the medical experimentation. Dr. White proclaimed, “[Blacks] bear surgical operations much better than white people and what would be the cause of insupportable pain for white men, a Negro would disregard... [I have] amputated the legs of many Negroes, who have held the upper part of the limb themselves.”¹⁴⁴ Such an example of amputation was a slave who had a tenacious leg ulcer. The slave’s leg would not immediately respond to the medical staff’s procedure so the surgeon decided to cut the leg off. There were other possibilities but the surgeon chose the most extreme option. The surgeon was reprimanded and was required to have to consult two professors in cases, “requiring an operation which may hazard the life of the patient or maim him.”¹⁴⁵ Such a case was rare to see accountability for malpractice on a slave’s body. It is a possibility that the medical staff was worried that the slave’s owner would hold them liable destroying his property. Regardless, the perception of the surgeon’s actions was due to the general notion of black durability in the medical community, which was promoted by Dr. Johnson.

Dr. Johnson was the editor of the influential *London Medical and Chirurgical Review*. Johnson stated, “When we come to reflect that all the women operated upon in Kentucky, except one, were Negresses and that these people will bear anything with

¹⁴³ Washington, *Medical Apartheid*, 57.

¹⁴⁴ Ibid., 58.

¹⁴⁵ Savitt, *Medicine and Slavery*, 288.

nearly if not quite as much impunity as dogs and rabbits, our wonder is lessened.”¹⁴⁶

Also, Dr. Thomas Hamilton testing the idea of black heat tolerance experimented on a slave named John Brown. Hamilton placed Brown into a makeshift open-pit oven trying to develop sunstroke medication. Brown stated that Hamilton, “Peeled off layers of his skin to determine how thick my black skin went.”¹⁴⁷

From 1846-1847, Dr. Walter F. Jones of Petersburg wanted to examine a cure for typhoid pneumonia. There was no exact number of individuals that were involved in the experiment but the patients that were involved were black. One patient was a twenty five year old slave. Jones explained,

The patient was placed [naked] on the floor on his face, and about five gallons of water at a temperature so near the boiling point as barely to allow the immersion of the hand, was thrown immediately on the spinal column, which seemed to arouse his sensibilities somewhat, as shown by an effort to cry out; he was well rubbed and wrapped in blankets, and removed to bed. If necessary, the treatment was to be repeated in four hours.¹⁴⁸

Jones asserted that many were cured from typhoid pneumonia by this technique that reestablished the capillary circulation of the patient. Overtime, Jones’ procedure proved to be false.

One doctor that used medical experimentations that changed the physiological understanding of women and created the medical specialty gynecology was South Carolina born plantation physician J. Marion Sims. He believed in the idea of black durability. Literature like *The Biology of the Negro* and *SMJ*, influenced Sims perception of black women. The book states, “Women living under primitive conditions, as do most

¹⁴⁶ Washington, *Medical Apartheid*, 58.

¹⁴⁷ Fett, *Working Cures*, 152.

¹⁴⁸ Savitt, *Medicine and Slavery*, 299.

native Africans, go through pregnancy and delivery with comparative ease and little inconvenience.”¹⁴⁹ In 1932, *SMJ* mentioned, “The colored woman because of her lessened sensibility to pain, is willing to endure a prolonged natural labor when a white woman would hours before be demanding relief.”¹⁵⁰ Black women’s “genital hardness” was the justification of unanesthetized (no application of anesthesia) experimentations and influenced Sims’s unanesthetized experimentations on slave women. For example, the introduction of the cesarean section procedure was very dangerous to the mother and infant. Enslaved women were used until the procedure was perfected and deemed harmless.¹⁵¹

Sims used eleven slaves to perform experimentations. His experimentations were not bias by sex. For example, Sims operated on a nineteen year old slave male by the unanesthetized removal of bone segments to prevent the spread of infection.¹⁵² Sims infamous gynecological experiments took place in a Montgomery, Alabama with many subjects under the age of twenty. From 1845-1849, his experimentations were on slaves Anarcha, Betsey, Lucy and others who suffered from vesico-vaginal fistula (VVF). VVF is an abnormal fistulous tract extending between the bladder and the vagina that allows the continuous involuntary discharge of urine into the vaginal vault.¹⁵³ VVF was a common condition for women in the nineteenth and twentieth century with no bias towards a woman’s socioeconomic status and caused social isolation due to the atrocious odor it caused.

¹⁴⁹ Hoberman, *Darwin's athletes*, 178.

¹⁵⁰ Ibid.

¹⁵¹ Fett, *Working Cures*, 151.

¹⁵² Washington, *Medical Apartheid*, 63.

¹⁵³ Savitt, *Medicine and Slavery*, 297.

Sims invented the vaginal speculum a device that opens up the vaginal canal for medical examination.¹⁵⁴ His examination left slave women completely vulnerable with no sense of respect and privacy. Slave women were completely naked. Sims, prominent citizens, and local apprentices visually examined the women while several of his colleagues took turns inserting his speculum.¹⁵⁵ Sims declared, “I saw everything as no man had seen before.”¹⁵⁶

Through his procedures slave women were constrained in order to make incisions within the vagina. Sims never confirmed to have a successful procedure of VVF but most assumed he did. His colleague, assistant, critic Dr. Nathaniel Bozeman claimed he had to fix his VVF procedure in an occurrence when VVF was created by Sims removing bladder stones from a nine year old slave girl.¹⁵⁷ Sims was outraged and defended his successes correcting VVF. However, history of medicine tells us Sims was not the pioneer in VVF repair. In 1838, Virginian surgeon Peter Mettauer operated on twenty five women in Prince Edward County, Virginia. Mettauer only cured one woman, which he blamed the lack of intercourse prevention as the reason his women subjects did not heal.¹⁵⁸

Sims and other physicians abused black slaves to explore bodily reactions to drugs and procedures causing physical and psychological harm. The race-based idea of black hardiness falsely justified acts of maleficence because black individuals were different and really could handle the pain. Furthermore, the notion of black hardiness

¹⁵⁴ Washington, *Medical Apartheid*, 64.

¹⁵⁵ Ibid.

¹⁵⁶ Ibid.

¹⁵⁷ Ibid., 67.

¹⁵⁸ Savitt, *Medicine and Slavery*, 298.

sustained the contradiction that black bodies were inferior and simultaneously physically superior. The trend of black body hardness, being a tool for experimentation, continued in the United States military.

Military Experimentation

In World War II, the United States Office of Scientific Research and Development (OSRD) Army's Chemical Warfare Service and the Naval Research Laboratory conducted mustard gas experiments on 60,000 American Soldiers with at least nine race-based research projects based on race, pigment, and complexion.¹⁵⁹ Physicians wanted to determine African Americans, Asians (Japanese), and Hispanics' (Puerto Ricans') susceptibility to and injury from mustard gas with whites being the control group. The involuntary experiments, considered to be one's patriotic honor to participate, were based on preparatory measures in case soldiers had to prepare for chemical warfare.

The mustard experiments had three goals. American soldiers were trained in the event that they were attacked by mustard gas, the effectiveness mustard gas had against the enemy, and racial differences biologically. This was accomplished by the evaluation of specific clothing, gas masks, and skin applications (ointments). In what was called a "drop test" or "patch test" mustard agent was applied to soldiers' bare skin, which caused immediate and severe eye injuries, burns, oozing sores and blistering on the face, hands, underarms, buttocks, and genitals, which resulted in "lung damage, psychological disorders, cancer, asthma, emphysema, cancer, asthma, emphysema, and eye problems,

¹⁵⁹ Smith, "Mustard Gas and American Race-Based," 517-518.

and blindness.”¹⁶⁰ Other known tests were “field tests” and “man-break tests.” In the field tests, soldiers were sprayed with mustard gas wearing different forms of protective clothing and scientists who organized the man-break tests placed soldiers in mustard gas chambers to examine their stamina before incapacitation.¹⁶¹ The mustard gas experiments were tools to confirm racial difference. Jim Crow law influenced the military’s treatment of minorities and where experiments involving minorities took place.

African American, Japanese American, and Hispanic American units were segregated. At least, four research projects compared mustard gas exposure in African American soldiers and Japanese American soldiers to white soldiers.¹⁶² African American and Hispanic men were used for defensive purposes. Black and Hispanic men’s susceptibility to mustard gas (compared to white men) would determine their function on the front lines. The tests on Japanese Americans were for offensive purposes.

Such experiments were conducted at Cornell University Medical College, the University of Chicago Toxicity Laboratory, the Institute for Medical Research in Cincinnati, and the Rockefeller Institute for Medical Research.¹⁶³ Cornell University suggested racial differences in mustard gas exposure. Cornell stated, “All investigators agree that the skin of Negroes [sic] as a group is much less sensitive to mustard gas than the skin of whites. About 78 per cent of negroes [sic] are ‘resistant’ as compared with 20-40 per cent among the whites.”¹⁶⁴ Cornell’s rationale for its finding was the ingrained appropriations of blacks having thicker skin. Ultimately, the 1946 report by the OSRD

¹⁶⁰ Smith, “Mustard Gas and American Race-Based,” 518.

¹⁶¹ Ibid.

¹⁶² Ibid., 518-519.

¹⁶³ Ibid., 519.

¹⁶⁴ Ibid.

and the National Defense Research Council concluded that the racial testing of African Americans was not conclusive. Medical scientists did not mention racial categories in their conclusions but admitted their experiments as social constructs. The scientists concluded, “Race provided little, if any, meaningful health information.”¹⁶⁵ The mustard gas experiments were recently resurfaced by National Public Radio (NPR) and Public Broadcasting Service (PBS) in 2015.

In 1956, the Central Intelligence Agency (CIA) and US Army personnel implemented “Operation Big City.” Operation Big City was a secret biological warfare experiment executed in numerous East Coast cities.¹⁶⁶ It was in the CIA’s interest to confirm if different lung disease causing fungi affected blacks more than whites. The fungi were applied in employment areas which were dominantly occupied by black employees. The purpose of the experiment was, “within this [supply] system, there are employed large numbers of laborers, including many Negroes, whose incapacitation would seriously affect the operation of the supply system.”¹⁶⁷ Other fungal experiments happened in the California Valley and affected blacks and Asians, which also resulted in minorities more susceptible to fungal infection than whites. The fungi experiments have not been acknowledged by the US government. The US government continued experimentation through plutonium experiments.

During World War II, Ebb Cade, a fifty three year old African American, worked as a cement mixer at the secret weapons production plant in Oak Ridge, Tennessee. Cade got into an automobile accident on his way to work, which resulted in a cut lip and nose

¹⁶⁵ Smith, “Mustard Gas and American Race-Based,” 520.

¹⁶⁶ Washington, *Medical Apartheid*, 382-383.

¹⁶⁷ *Ibid.*, 383.

and a fractured right kneecap, forearm, left femur, and thigh bone.¹⁶⁸ He was kept at the Manhattan Engineer District Hospital (Oak Ridge Army Hospital) in Oak Ridge, Tennessee. Cade (known as patient HP-12) was injected (without consent) with 4.7 out of 5 micrograms of plutonium by Los Alamos Chemist Wright Langham.¹⁶⁹ Cade's dosage is considered low but the lack of consent makes his case notorious. Plutonium is a highly toxic element being purified to make atomic bombs.

Cade was thoroughly monitored with his dosage purposely imitating the emission ratio in a lab worker. His blood, bone, urine, and stool examined within hours of his plutonium injection. Cade's fifteen teeth decayed and were pulled out for sampled plutonium. He was the first out of eighteen subjects who were apart of a plutonium experiment in the federally sponsored Manhattan Project, under contract to the US Atomic Energy Commission (AEC).¹⁷⁰

The Manhattan Project was the code name given to the program to build an atomic bomb. The AEC succeeded the Manhattan Project. It was involved in the development of atomic energy and created legislation for radiation research with human subjects. Blacks accounted for 60% of the human subjects in the Manhattan Project.¹⁷¹ The purpose of the plutonium experiments was to test the toxicity of this radioactive chemical element. Other recorded plutonium subjects were,

A 68 year old man with advanced cancer of the mouth and lung became the second subject. Then a 55 year old woman with breast cancer was injected ... and

¹⁶⁸ Welsome, Eileen. *The Plutonium Files: America's Secret Medical Experiments in the Cold War*. New York, N.Y.: Dial Press, 1999, 83.

¹⁶⁹ Moreno, Jonathan D. *Undue Risk: Secret State Experiments on Humans*. New York: W.H. Freeman, 2000, 124-125.

¹⁷⁰ Welsome, *The Plutonium Files*, 84.

¹⁷¹ Washington, *Medical Apartheid*, 219.

a young man with Hodgkin's disease on the same day, possibly at another Chicago area hospital. The older man with cancer received only 6.5 micrograms, but the breast cancer patient and the man with Hodgkin's disease received 95 micrograms.¹⁷²

The excretion ratio turned out to be less than animals, which made the examination of stool from the plutonium subjects an inadequate means to determine a person's physiological reaction to plutonium. Due to the infamous nature of this experiment, the AEC neglected the word plutonium and used the code terms "product" or "49."¹⁷³ The plutonium projects were continued with Elmer Allen.

Elmer Allen was a thirty six year old African American railroad porter for the Pullman Company. Allen hurt his knee from awkwardly falling off a train. His knee fracture would not heal. The Pullman Company would not accept liability for his injury, fired him, and did not give him any compensation. After dealing with his knee fracture and unemployment, Allen went to the University of California's clinic in San Francisco (UCSF).¹⁷⁴ Physicians concluded the reason his knee fracture would not heal was a result of chondrosarcoma (bone cancer).¹⁷⁵

Allen needed his left knee amputated. After his amputation, Allen (known as patient CAL-3) was injected with plutonium. Allen was injected with more toxic plutonium called "plutonium-238" compared to the eighteen subjects injected with "plutinoim-239."¹⁷⁶ He was the only subject given a consent form but full veracity and competency of the experiments was not disclosed. He was the last plutonium subject and outlived all of the plutonium subjects who died to causes not related to the plutonium

¹⁷² Moreno, *Undue Risk*, 126.

¹⁷³ Washington, *Medical Apartheid*, 219.

¹⁷⁴ Moreno, *Undue Risk*, 124-134.

¹⁷⁵ Washington, *Medical Apartheid*, 221.

¹⁷⁶ *Ibid.*

experiments. Allen died in 1991 due to pneumonia. Radiation trials were not the only experiments done on black bodies. Irradiation experiments were also popular in the mid-twentieth century.

University of Cincinnati's Radiologist Eugene Saenger spearheaded the Total Body Irradiation (TBI) experiments. From 1960 to 1971, contracts between the University of Cincinnati and the Defense Atomic Support Agency did experiments, "People with 'radio-resistant' tumors were irradiated if there was thought to be a chance of benefit to them and to learn about how the treatment effected them, especially psychological and psychiatric effects."¹⁷⁷ The purpose was both palliative and informational for military treatment in defense situations.

The first patient was a sixty seven year old black man with a cancer tumor on his left tonsil, which spread to his palate and throat. The sixty seven year old did not survive. A total of 200 subjects participated in the TBI experiments with 75% or 150 being African American.¹⁷⁸ None of the subjects were aware of the risks like bone marrow suppression and nausea. Saenger never mentioned the side effects to the subjects and in any experiment documentation. Consent was verbal with no record of what the subjects were told.

African Americans were not the only racial groups that participated in race-based experiments but were the most used, sought after, and endured the worst experiments. Such factors harmed black soldiers who already sacrificed their well-being and livelihood to fight for a country that would not fight for them in return. The military's race-based

¹⁷⁷ Moreno, *Undue Risk*, 212.

¹⁷⁸ Washington, *Medical Apartheid*, 233.

experiments created maleficence to black soldiers' bodies which affected their autonomy. Many of the black soldiers' physiological capacities and quality of life diminished due to the physical strain of experimentation. Military race-based experimentation opened different avenues for institutions to conduct experiments. The next area of race-based experimentation happened in the prison system.

Prison Experimentation

Holmesburg Prison in Philadelphia, Pennsylvania conducted abusive experiments (tests) on its inmates, from the 1950s to the 1970s. The tests were led by Dermatologist Dr. Albert M. Kligman. His research was on black and white men but the majority of his research was done on black men. For example, the dioxin experiments had 49 black inmates compared to 9 white inmates.¹⁷⁹ Kligman did experiments for Johnson & Johnson, Merck, Helena Rubenstein, Dupont, and many others.¹⁸⁰ After World War II (WWII), the United States was the only country allowing experiments done on its prison population. Many cosmetic and pharmaceutical companies capitalized off of Kligman's decades of research.

In the early 1960s, Al Zabala, a white twenty seven year old Philadelphian, was serving a sentence for burglary. His penalty was enforced at Holmesburg Prison in Philadelphia, Pennsylvania. Prisoners, like Zabala, could not survive without money. Employment in prison did not provide a lot of options. Your choices were jobs in maintenance, custodial, kitchen, library staff (if the prison had one) and other menial jobs. The compensation was not adequate for daily survival but becoming a test subject

¹⁷⁹ Hornblum, Allen M. *Acres of Skin: Human Experiments at Holmesburg Prison : a True Story of Abuse and Exploitation in the Name of Medical Science*. New York: Routledge, 1998, 171.

¹⁸⁰ Washington, *Medical Apartheid*, 249.

allowed opportunities for better compensation. At first, Zabala did not want to participate in the test but it was hard for him to resist. Zabala said, “It was something to do, the best game in town. The money was good and the money was easy.”¹⁸¹ The tests were something Zabala can make quick and adequate money, an idea that attracted many prisoners.

The usual prison worker pay was 15 cents per day, but being a test subject was so much more financially beneficial. Zabala went through numerous of tests that comprised of him using foot powder, deodorant, creams, and shampoos. The compensation for foot powder and deodorant tests was \$100 per month and hand cream tests were a \$1 a day.¹⁸² At that time, the prisoners felt the financial benefit outweighed the physical consequences. Zabala was apart of a test that he believes he was injected with a substance ten times the potency of Lysergic Acid Diethylamide (LSD) and was monitored for seven days. Zabala described his experience,

I wasn’t right for a month after the test. I was real subdued and quiet. I had problems swallowing food and a constantly dry throat. They put me on a liquid diet until I could swallow whole food again. When we finally came back to the population, all the guys on the study had to wear badges that said we were no responsible for our actions and if we acted up to get U of P personnel to come and get us. We had to wear badges for a month and once a week talked to the psychs. They made us take paperwork and association tests to measure our psychological condition.¹⁸³

Other prisoners who were subjects of the test had horrible hallucinations, trouble sustaining consciousness, self-violent, and violent temper tantrums.

¹⁸¹ Hornblum, *Acres of Skin*, 5-6.

¹⁸² *Ibid.*, 6.

¹⁸³ *Ibid.*, 7.

Another experience recorded was Black boxer Roy “Tiger” Williams. He served a 9 to 23 month sentence. Williams used an inmate named Sigmund Weitzman’s shampoo. Weitzman was using “hair lotion” given to inmates who volunteered to test the product. Williams became bald stating, “The lotion removed my hair and anything else I had on my head.”¹⁸⁴ Zabala’s experience, though not ideal in any means, was better than the black inmates. Black inmates were treated with immense bias.

Black inmates did not get the desirable tests and received lower pay compared to the white inmates.¹⁸⁵ Kligman tested 153 different types of substances between 1962 and 1966 on 75% of Holmesburg Prison inmates.¹⁸⁶ Most of the experiments done on African Americans had to do with their skin. Similar to the mustard gas experiments, Klingman was influenced by Jim Crow law. He created protocols that ordered racially separated experiments. Kligman specifically designated certain experiments for black and white men. For example, a 1957 experiment was,

Designed to promote the inoculation of human skin with ... ectodermotropic viruses such as wart virus... herpes simplex and herpes zoster was reserved for healthy, colored, male volunteers between the ages of 20 and 45 years of age. Another is experimental inflammation and inflammatory dermatoses targeted 10 healthy white subjects who were paid to submerge one arm in a sodium lauryl sulfate solution one hour a day for 55 days in a row.¹⁸⁷

Such skin experiments fortified the idea of thickness of black skin. Other studies of black epidermis continued.

In the 1967 *Journal of Investigative Dermatology*’s article, Klingman’s sodium lauryl sulfate (SLS) and sodium tetrachloro-phenol (STP) experiments were documented.

¹⁸⁴ Hornblum, *Acres of Skin*, 13.

¹⁸⁵ Ibid., 17.

¹⁸⁶ Washington, *Medical Apartheid*, 249.

¹⁸⁷ Hornblum, *Acres of Skin*, 17.

His findings suggest that SLS and STP were the best hardening agents for skin. Klingman concluded, “the solid hardening is attainable only if the skin passes through a very intense inflammatory phase with swelling, redness, scaling, and crusting.”¹⁸⁸ These experiments were excruciatingly painful and permanently discolored and disfigured black inmates’ skin. SLS and STP experiments concluded that “the Negro is more resistant to irritation.”¹⁸⁹ In 1971, Klingman conducted a staph infection study with 150 inmates from twenty five years old to forty years old. Most of the tests’ subjects were African American. Only three inmates became ill but the experiment cause lesions to form on inmates.

Holmesburg Prison’s significant legal problem was the W-2429 experiment. A total of nine black subjects between twenty three years old and thirty one years old were involved in the safety and tolerance of Wallace Laboratories’ W-2429 medication. One of the subjects Jerome Roach became ill four days after digesting temperature pills with a “sore throat, sore joints, fever, nausea, sores, and rashes.”¹⁹⁰ Roach did not receive adequate treatment from the prison physician, which resulted in him being taken to Philadelphia General Hospital. Roach stayed at Philadelphia General Hospital for several weeks. He found out that his illness was a result of different pills given to him from those prescribed. When Roach returned to Holmesburg Prison, he was denied sufficient medical treatment and medication. As a result, Roach sued Klingman but did not win the case because the court felt he was not “coerced” to be apart of the W-2429 experiment.

¹⁸⁸ Hornblum, *Acres of Skin*, 144.

¹⁸⁹ *Ibid.*, 145.

¹⁹⁰ *Ibid.*, 201.

The Holmesburg Prison was not the only criminal institution to conduct medical experiments. Sloan-Kettering Institute also conducted tests on prison inmates.

In 1952, Sloan-Kettering Institute's cancer tests were sponsored by the National Institutes of Health (NIH) and the PHS syphilis study at Tuskegee. Sloan's Dr. Chester M. Southam injected over 180 black Ohio State Prison's inmates with live human cancer cells.¹⁹¹ Southam's objective was to see how a healthy human body would react to cancer cells. He was interested to see how cancer cells were neutralized and killed in healthy subjects. Southam did not disclose the full risk of the experiments to the black inmates.

Between 1967 to 1969, Kilby, Draper, and McAlester prisons conducted blood-plasma trials in Alabama. The trials purpose was to test blood transfusions by using large quantities of plasma. Dr. Austin R. Stough managed the experiments. He was criticized because the experiments were disorganized with no informed consent and accurate records. Also, Stough's management also failed to keep the area of experiments clean. The disorganization and unsterile process of the blood-plasma trials led to inmates' death and sickness. Twenty eight percent of subjects developed hepatitis.¹⁹² Many subjects (black and white) died because of the unsterile trial areas and blood transfusions of the wrong blood type.

Another incident of prison experiments was at Tulane University. In the 1950s, Tulane University conducted psycho surgery experiments (funded by the CIA) on black inmates with no informed consent. Tulane Psychiatrist Robert Heath purposely selected black subjects to participate in experiments. Heath's experiments involved inserting

¹⁹¹ Washington, *Medical Apartheid*, 252.

¹⁹² *Ibid.*, 253.

electrodes into subjects' brains in order to stimulate the part of the brain that transmits pleasure.¹⁹³ Also, Heath and Harry Bailey (Heath's assistant) participated in trials using LSD and bulbocapnine at Louisiana State Penitentiary. The LSD and bulbocapnine affected an individual's faculties and cognition, which was used to control violent prisoners. The experiments were conducted exclusively on black inmates with no informed consent. The CIA wanted to collect data if the two substances induced, "loss of speech, loss of sensitivity to pain, loss of memory, loss of will power and an increase in toxicity in persons with a weak type of central nervous system."¹⁹⁴ The LSD experiment was an example of how race-based experimentation in the prison system aided in understanding how bodies react to certain diseases and procedures.

The use of black prisoners was very popular in race-based experimentation in prisons. Many of the prisoners died before being released or had a poor quality of life that affected their daily autonomy. Such prison and military experiments happened after a global consensus to stop unethical treatment on human subjects.

International Codes and Ethical Standards

The Nuremberg Code and the Declaration of Helsinki are useful tools in how research on human beings should be conducted. In 1947, The Nuremberg Code (also known as the Doctors' Trial) was a series of ten principles developed by American judges who responded to Nazi doctors who conducted human experiments on concentration

¹⁹³ Washington, *Medical Apartheid*, 254.

¹⁹⁴ Ibid.

camp inmates.¹⁹⁵ It is the foundational document that served as a blueprint for today's principles on human subjects involved in experiments and medical research.

In 1964, the Declaration of Helsinki was adopted by the World Medical Association. It was constructed to, “meet the threat that inappropriate research posed both to the integrity and the reputation of the research enterprise.”¹⁹⁶ It added three significant factors to the Nuremberg Code. The distinction between clinical therapeutic research and nontherapeutic biomedical research, an advocacy mechanism to enforce that the principles are followed, and the proxy consent by family members when the subject cannot consent.¹⁹⁷ It is imperative that the highest level of efficacy in research be used for the improvement of the human condition.

The experiments mentioned previously (with the exception of slave experiments) were conducted after these ethical laws were in place.¹⁹⁸ There was not any compliance and penalties for experiments specifically on African Americans, which showed the legacy of race-based experimentation, influenced ongoing medical practices. American medicine created laws they did not follow and mocked the value of clinical ethics. Allowing such treatment of African Americans is a violation of internationally agreed upon commitments.

Research ethics emphasize respecting the autonomy of participants. It is the commitment to “building up or maintaining others’ capacities for autonomous choice

¹⁹⁵ Brody, Baruch A. *The Ethics of Biomedical Research: An International Perspective*. New York: Oxford University Press, 1998, 33.

¹⁹⁶ Ibid., 34.

¹⁹⁷ Ibid.

¹⁹⁸ Slave experiments happened centuries before international codes were created. Therefore, it is not feasible to include slave experiments in this section.

while helping to allay fears and other conditions that destroy or disrupt autonomous actions.”¹⁹⁹ The realities of military and prison experiments on black bodies did the complete opposite. Research was performed without informed voluntary consent of participants. To be balanced, informed consent was not even thought of until the late 1950s and put into examination of clinical trials until the early 1970s.²⁰⁰ However, due to sustained racist perceptions, black bodies were not held under the same consideration.

Informed consent allows patients or participants to be aware of the “nature and results (the potential risks and benefits) of each course of actions open to them before they make their decision.”²⁰¹ Military and prison experiments did not disclose any potential risks and benefits violating informed consent as a key procedure in the clinical process. Specifically, prison experiments were coercive using monetary means to attract participants. To be clear, monetary incentive can be a useful means to compensate participants for their involvement in trials. The ethical issue with the mentioned prison experiments was money was the reason for participants’ involvement in trials.

Adequate compensation was a challenge for prisoners. The prison and clinical trial directors knew about the prisoners’ financial struggles and used monetary resources as a means to get participants. Informed consent minimizes the chance that people will be deceived, exploited, tricked, misled, duped, manipulated, or pressured so that their autonomy is violated.²⁰² Informed consent was not used because the prisoners’ autonomy

¹⁹⁹ Beauchamp, *Principles of Biomedical Ethics*, 103.

²⁰⁰ *Ibid.*, 117.

²⁰¹ Steinbock, Bonnie. *The Oxford Handbook of Bioethics*. Oxford University Press on Demand, 2007, 218.

²⁰² *Ibid.*, 217.

and decision making was violated through monetary means. Another issue was the inconsideration measuring the risks and gains of trials.

In clinical trials, the participants' gains anticipated from the experiment must commensurate with the risks. The results of loss, injury, and deformation of prisoner participants completely outweighed the gains of the prison trials. Similar results were found with the military trials. The prisoner and military experiments were nontherapeutic biomedical research which solely had scientific value toward the participants. Yet, the ethical issues with the military and prison experiments were the special interest of a few took precedence over the well-being of the participants.

Military and prison experimentation did not follow the ethical commitments required in clinical trials. The codes and declarations of conduct in research without proper enforcement do a disservice to such policies themselves. The autonomy of participants are manipulated and unacknowledged, which hinders the outcome of non-maleficence, beneficence, and justice being practiced. Other racial groups were involved in military and prison experiments but blacks endured the worst procedures. As a result, there are core consequences that developed in the black community.

Black Community's Response to Race-based Experimentation

For centuries, race-based experimentations manipulated the black body as a Guinea pig to explore biological and physiological understanding for medical progression. This unique medical history of minorities (especially African Americans) developed an uncomfortable relationship in medicine. It is logical to perceive that such histories of medical experiments on black individuals fractured the psyche of the black

community's thoughts and involvement in American medicine. African American reactions of medical experiments developed a language of distrust, which has heavily impacted black oral tradition in medicine.

Black Oral Tradition

Oral tradition is a significant part in black culture. Tradition, ideas, and experiences are verbally passed down from generation to generation. Oral tradition is understood to be, "the transmission of cultural items from one member to another, or others. Those items are heard, *stored in memory*, and when appropriate, recalled at the moment of subsequent transmission (*Emphasis Added*)."²⁰³ The realities of medical experimentation among African Americans became stories within oral tradition that are heard, stored, and recalled. When blacks individually and collectively interact with the clinical or medical process, the memories of mistreatment of friends, living family members, and predecessors are relived and processed. The black individual may not have experienced or lived medical experimentation but feel a sense of association because of the unique racial history in American society. The notion is not individual but collective. If it happened to him or her, it can happen to me.

Furthermore, oral tradition is a preservation mechanism.²⁰⁴ Stories and experiences are preserved along with feelings and emotions. It is through such language that blacks developed their own view of reality and society. The oral tradition of African Americans is a product of their environment in medicine. It is a reminder on how

²⁰³ Mugalu, Joachim. *Philosophy, Oral Tradition and Africanistics: A Survey of the Aesthetic and Cultural Aspects of Myth, with a Case-Study of the "Story of Kintu" from Buganda (Uganda), As a Contribution to the Philosophical Investigations in Oral Traditions*. Frankfurt am Main: P. Lang, 1995, 54.

²⁰⁴ Ibid., 56.

medicine and society expresses and reflects itself toward African Americans. Such inhumane and racist medical treatment influenced blacks distrust toward American medicine. Blacks' distrust of American medicine had its origins from slavery.

Black slaves' oral traditions reported the abuses of the black body on plantations. Slaves did not want to take what they called "white man's medicine" or "white medicine," because of anxiety and fear. Slaves acted like they were not sick so they would not have to see white doctors and take white medicine. Slaveholders noticed the apprehension of blacks. A Mississippi planter said, "The Negroes unfortunately for themselves and equally so for us had no confidence in our treatment- they said it was certain death to take our medicine and we were compelled to stand by and see them die."²⁰⁵ Slaves distrust heightened when they were forced to take white medicine or get punished.

There was always an issue for the slave to follow white doctor's orders to take white medicine and stay in bed. Blacks did not want to go to slave hospitals or infirmaries and often were forced to go as a last resort. A Richmond, Virginia newspaper commented,

Among them there prevails superstition that when they enter the [medical college] infirmary they never come out alive; (although servants are no where better treated and taken care of than in that establishment;) therefore they will not complain, but will often conceal their real condition until too late to do good.²⁰⁶

This extremely contradictory statement by the Richmond newspaper suggests the historical disconnect between whites' understandings and slave's perception of care. If medical care was adequate slaves would not be so reluctant to be treated at slave

²⁰⁵ Fett, *Working Cures*, 147-148.

²⁰⁶ Savitt, *Medicine and Slavery*, 283.

hospitals, infirmaries, and other medical establishments. The inhumane treatment and abuses experienced by slaves made it completely logical for them to avoid white medicine and clinics at all costs. The slaves' oral tradition of their experience and perception of American medicine influenced their participation in such a system. Through oral tradition, such experiences permeate blacks' memories. The historical strain American medicine has on blacks affects the group's language and understanding of care. Ultimately, American medicine's racist history resulted in blacks' poor health literacy.

Health literacy is not exclusive to reading and writing but, "the wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life."²⁰⁷ Health literacy at its core stresses veracity and probity, which blacks did not experience. However, these two qualities can change because health literacy is a continuing process. In the black community, oral tradition shapes one's health literacy. It informs the process and interaction of African Americans in American medicine and care.

As Dr. Christina Zarcadoolas suggests, "Health literacy evolves over one's lifetime and like most other complex human competencies, is affected by health status as well as demographic, sociopolitical, psychosocial, and cultural factors."²⁰⁸ The 246 years of chattel slavery possessed numerous lifetimes and generations of black slaves that did not have the adequate health literacy and care that could be offered in those time periods because of a society and system that imposed their value as less than human. Such

²⁰⁷ Zarcadoolas, Christina, Andrew F. Pleasant, and David S. Greer. *Advancing Health Literacy: A Framework for Understanding and Action*. San Francisco, CA: Jossey-Bass, 2006, 5-6.

²⁰⁸ Ibid., 55.

realities were passed down in black oral tradition. As a result, blacks had improper or no use of medication, no use of health services, poor self-management of chronic conditions, inadequate response in emergency situations, poor health outcomes, lack of self-efficacy and self-esteem, and social inequity.²⁰⁹ In order to survive, blacks had to create their own system of treatments and medications to survive in a racist society.

Black Homeopathic Medicine

Black homeopathy (also known as homeopathic medicine) is a medical system that offers a variety of approaches to medicine (i.e. herbal, botanical, traditional, psychological, and spiritual).²¹⁰ Homeopathic medicine has been understood as a German development credited to German physician Samuel Hahnemann in the eighteenth century. However, homeopathy's origin dates back to ancient African tribes who incorporated nature's surroundings as their physical and spiritual source of healing. Sacred power, spiritual healing and nature were used as collective processes of healing.

American homeopathy began with Native Americans and expanded with black slaves. Blacks and Native Americans were enslaved together and meshed their histories of homeopathy together.²¹¹ Black homeopathy continued in the early to mid-seventeenth century by black slaves and Native Americans as a necessary method to survive the daily physical burden of slave work. Through the resource of oral tradition, blacks' home remedies, treatments, and plant and herb knowledge were passed down from generations as a response of self-preservation.

²⁰⁹ Zarcadoolas, et al., *Advancing Health Literacy*, 1-2.

²¹⁰ Covey, *African American Slave Medicine*, 42.

²¹¹ Fett, *Working Cures*, 64.

Plants like sesame, yams, okra, and black eye peas originated in Africa and grown in American plantations. Slaves used licorice plants for coughs and fevers, okra leaves as poultices (soft moist mass) applied to the body to relieve soreness and inflammation, Jamaican senna as a laxative, “Surinam poison” for chronic sores, kola seeds for belly pains, mackaroot tea to cure worms, pepper/dogwood tea for fevers, snakeroot for stomach aches, and collard leaf as a cure for headaches.²¹² Blacks protected these medical traditions by secretly sharing with caution. White doctors only paid attention to black homeopathy when a slave made a great medical discovery. For example, a slave named Caesar received a 300 pound pension for treating poisoning and snake bites.²¹³

Whites felt threatened by black homeopathy and viewed it as “native,” “negro superstition,” “voodoo,” or “hoodoo.”²¹⁴ There was a legitimate fear that black homeopathy and its spiritual elements would spread and challenge Christianity. As a response, in 1748, Virginia passed laws to prohibit blacks from practicing homeopathy. In 1749, South Carolina’s general assembly passed a law prohibiting slaves from being employed by physicians and distributing treatment.²¹⁵ Regardless of these laws, whites used black homeopathy for treatment because they felt it was more efficacious compared to what white doctors had to offer. Slaveholders personally preferred black practitioners over whites. Slaves who had no human and citizen rights uniquely garnered medical status by traditional knowledge of black homeopathy. Blacks became herbalist, practitioners, and doctors of Botany (the science of plants) or “Negro Medicine.” Black homeopathy revolutionized American pharmacopoeia (the making of drugs).

²¹² Fett, *Working Cures*, 63-71.

²¹³ Covey, *African American Slave Medicine*, 44.

²¹⁴ Ibid.

²¹⁵ Ibid., 43.

Blacks used botanicals for many purposes. Women used honeysuckle and rose petals as perfume, men used barks for belt, and children used twigs and whistle for games. Black herbalists believed blood quality was the key factor for diagnosis and an indicator of health status. Black herbalists used many remedies to purge out sickness in the blood. The most popular used was the sassafras root made into a tea. It was believed the tea, “searches de blood and finds out what’s wrong and goes to work on it.”²¹⁶ Such ingenuity and sophistication of African Americans’ understandings of herbs, plants, and other resources challenged the status quo of black intellectual inferiority.

Blacks’ dualistic reaction to atrocious clinical care and experiments sustained the oral tradition of fear and health illiteracy but resulted in black homeopathy. Black homeopathy was the slaves reaction; a good consequence of unethical medical behavior. It made a racist medical system aware that African Americans and other minorities are valuable and can contribute to the progression of medicine. Black homeopathy became the medium of clinical justice, the means to participate and be heard in the clinical process. The misappropriations of black body and race-based experiments have left deep wounds in minority communities, but black homeopathy was a means of medical sanity.

Race-based medicine was the catalyst that warranted African Americans bodies as a different entity that has unique functions. Such ideas promoted experimentations that critically fractured blacks’ relationship with clinical care and physicians. However, black homeopathy began the process of African Americans’ reconciliation and contribution to medicine. In chapter three, I will examine race-based medicine in its pharmaceutical form in a drug called BiDil along with its history, development, approval, and the financial,

²¹⁶ Fett, *Working Cures*, 75.

scientific, genetic and racial tensions it produces with suggested solutions to race-based medicine through physicians perfecting their cultural competency, empathic communication, and awareness with a focus on diet and nutrition.

Chapter 3

RESEARCH, PHARMACOLOGY AND PROFIT IN RACE-BASED MEDICINE

Health disparity based on racial categories has been a popular topic for quite some time. Health challenges among American minority populations are no secret. Individuals within the African, Hispanic, and Asian communities are the most disadvantaged. The use of Pharmacology (the branch of medicine focusing on the knowledge and study of drugs) is used as a tool to alleviate health issues in minority communities. Specifically, heart failure is a major American public health issue. Compared to other races, African Americans suffer disproportionately higher rates of heart failure. BiDil was designed to specifically treat African Americans, which made BiDil the first drug to be categorized as race-based medicine. This chapter will examine significant heart studies before BiDil, BiDil's process to approval and its aftershock regarding race in the areas of economics, medicalization, and genetics with physician-patient critiques and nutritional solutions.

Before BiDil

Up until the mid-twentieth century, there were studies regarding the effects of cardiovascular disease not its causes. The three types of heart disease, categorized in 1928, were rheumatic, syphilitic, and arteriosclerotic.²¹⁷ In 1948, the United States Public Health Service (USPHS) (formally known as the National Heart Institute (NHI) and currently called the National Heart, Lung, And Blood Institute (NHLBI)) began an important study within the arena of cardiology. The USPHS partnered with the Massachusetts Department of Health and Harvard's Department of Preventative

²¹⁷ Pollock, Anne. *Medicating Race: Heart Disease and Durable Preoccupations with Difference*. Durham: Duke University Press, 2012, 31.

Medicine to create the Framingham Heart Study (FHS).²¹⁸ Cardiovascular studies before FHS suggested factors of cardiovascular disease after the patient had it. The purpose of the FHS study was, “To study the expression of coronary artery disease in a normal or unselected population and determine the factors *predisposing* to the development of the disease through laboratory experimentation and long-term follow up of such a group (*Emphasis Added*).”²¹⁹

FHS was based out of Framingham, Massachusetts (population of 28,000 in 1949) with 5,209 patients all white men and women between the ages of 30 to 62 with children being added later in 1971.²²⁰ It is important to note none of these patients had serious symptoms of cardiovascular disease and did not have prior cardiovascular episodes (i.e. heart attack or stroke). The patients’ follow up was in a five to ten year period. FHS’ goal was to find connections between the patients’ lifestyle, test results, and heart disease, which set the precedence for how future studies conduct measures for cardiovascular disease factors.

Doctors in the mid-twentieth century suggested stress was a factor that can contribute to illness. The medical mindset of that time understood the heart as an important organ reflecting the cause and management of stress. The daily demands in modernity caused stress on the heart and the tool of medicine can alleviate cardiac stressors. FHS supporter Dr. Paul Dudley White, the Father of American Cardiology,

²¹⁸ Aronowitz, Robert A. *Making Sense of Illness: Science, Society, and Disease*. Cambridge, U.K.: Cambridge University Press, 1998, 118.

²¹⁹ *Ibid.*, 55.

²²⁰ Pollock, *Medicating Race*, 54.

asserted, “stress and strain” in modern times should not be overlooked but should be an essential piece in learning more about cardiovascular disease.²²¹

Cardiovascular disease was not an African American issue but a white issue. In 1921, twenty seven years before FHS, Dr. Haven Emerson reported to the Massachusetts Medical Society, “The white race is more susceptible to heart disease than the colored race.”²²² Furthermore, in 1930, University of Pennsylvania’s Dr. C.C. Wolferth asserted to the New York Times, “Degenerative diseases of the heart and blood vessels comprise what is probably the most important problem facing the *white race* (*Emphasis Added*).”²²³ Even Dr. Paul Dudley White claimed that a “full-blooded Negro”²²⁴ did not get cardiovascular disease. However, there were rare arguments by individuals like Drs. Edward Schwab and Victor Schulze who suggested African Americans had more heart disease and worse mortality rates than whites.²²⁵ Cardiology and modernity were linked by racial discourse which brought a narrative that stress was associated with “whiteness.”

Dr. Stewart R. Roberts who was the Professor of Clinical Medicine at Emory University (1915-1941), President of the Southern Medical Society (1924-1925), and President of the American Heart Association (AHA) (1933-1934) compared whites as stressed and African Americans as joyous and carefree. Roberts said,

The white man, particularly those living lives of stress in urban conditions of competition, work and strain, makes his little plains and layups cares and riches and takes much thought of the morrow; the negro knows his weekly wage is his fortune, takes each day as it is, takes little or no thought of the morrow, plays, and

²²¹ Aronowitz, *Making Sense of Illness*, 131.

²²² Pollock, *Medicating Race*, 32.

²²³ Ibid.

²²⁴ Ibid., 28.

²²⁵ Ibid., 36-37.

lives in a state of play, hurries none and worries little. What must it be to live unhurried, unworried, superstitious but not ambitious, full of childlike faith, satisfied, helpless, plodding, plain, patient, yet living a life of joy and interest?²²⁶

The founding fathers of cardiology profoundly influenced the medical narrative of cardiovascular disease by their racial discourse.

Cardiology titans like Emerson, Wolferth, White, and Roberts created a medical narrative that constructed white individuals as victims of stress by a societal burden of responsibility, while establishing African Americans as the bystanders in societal progress. Roberts diagnosed this societal burden as “neurasthenia.” Neurasthenia is a late nineteenth century term that described physical and mental fatigue, dizziness, headaches, bodily pains, concentration difficulties, sleep disturbance, and memory loss.²²⁷ Neurasthenia was an epidemiological persuasion as “the white man’s burden.” A disorder that was the result of the heavy weight of responsibility whites had for the sake of American progress.

A key evaluation about the FHS, cardiovascular disease and modernity was all of the research was solely based on the representation of “white” individuals. FHS’ “diversity” was described by the European location of the patients (i.e. England, Italy, Poland, Greece, Ireland, and French Canada). The exclusion of African Americans in clinical research was not out the ordinary. As a matter of medical and historical truth, African Americans clinical exclusion was normal. As discussed in chapter one, eugenic influences on race ideology and perception influenced the medical world’s view of African Americans’ personhood, which cardiology was not an exception. Eugenic logic

²²⁶ Pollock, *Medicating Race*, 34.

²²⁷ Schwartz, Pamela Yew. “Why Is Neurasthenia Important in Asian Cultures?” *Western Journal of Medicine*. 176.4 (2002), 257–258.

was to dismiss individuals that were viewed as “less than human” and lacked human agency in clinical research and focus on individuals that were viewed as “genetically fit” to be the legitimate representation of American society. African American mortality was not viewed as important for the progression of modernity, an idea that was emphasized in early cardiology practice.

FHS’ influence is unprecedented. FHS spearheaded the emphasis of 1960s risk factor approach in the medicine community. The term “risk factor” was first used in a FHS investigators’ report in 1961 and the core of new heart related research in the late twentieth and twenty first century was based from FHS.²²⁸ FHS findings suggested the factors of cardiovascular disease were caused by physiologic function (body function), poor diet, family history, individual behavior, high blood pressure, diabetes mellitus (different types of diabetes), genetics, and hyperlipidemia (abnormally high concentration of fats or lipids in the blood).²²⁹ These findings show that there are numerous factors that may cause cardiovascular disease. FHS’ introduction of risk factors did not only open the medicine world’s eyes to aid in the prevention of cardiovascular disease but caused inquiries about the unknown risk factors of other diseases.

In the 1970s, hydralazine and isosorbide dinitrate (H/I) were discovered as key ingredients in drugs used to fight against heart failure and cardiovascular disease. In the 1970s, two Veterans Administration Cooperative Studies known as Vasodilator Heart Failure Trial (V-HeFT) I and II. V-HeFT I was developed and implemented from 1980-1985. The patient population of V-HeFT I came from many racial backgrounds who were already taking digoxin and a diuretic. The participants were broken into three groups by

²²⁸ Aronowitz, *Making Sense of Illness*, 119.

²²⁹ *Ibid.*, 131.

random selection. Group one received a placebo, group two received prazosin, and group three received the H/I combination. The findings suggested the placebo and prazosin were not effective. However, the investigators of V-HeFT I came to the conclusion that the H/I combination was an “effective new treatment for heart failure regardless of race.”²³⁰ The V-HeFT I trial laid the foundation for the V-HeFT II trial.

The V-HeFT II trial (1986-1991) compared the H/I combination to an angiotensin-converting enzyme (ACE) inhibitor called enalapril. ACE inhibitors widen or dilate blood vessels to improve the amount of blood flow the heart pumps, which helps to decrease the amount of work a heart has to do. Also, ACE inhibitors help in lowering blood pressure. The findings suggest the enalapril group had a positive mortality rate, but the H/I combination group had numerous results because the H/I combination’s efficacy and side effects varied. The findings were confirmed in a report asserting, “20 per cent to 30 per cent of congestive heart failure patients do not respond favorably to standard therapies of diuretics, digitalis or ACE inhibitors... particularly ACE inhibitors.”²³¹ Medical discourse on risk factors continued to permeate through the twentieth century through the Jackson Heart Study (JHS) in 1987.

JHS was based out of a concern by the founder of the Association of Black Cardiologists (ABC) Dr. Richard Allen Williams, for long-term observation of cardiovascular risk factors. Williams challenged the relevance of FHS in the African American community and wanted an African American version of FHS. JHS

²³⁰ Kahn, Jonathan. “Exploiting Race in Drug Development: BiDil’s Interim Model of Pharmacogenomics.” *Social Studies of Science*. Sage Publications, Ltd. Oct2008, Vol. 38 Issue 5, 738.

²³¹ Kahn, Jonathan. *Race in a Bottle: The Story of BiDil and Racialized Medicine in a Post-Genomic Age*. New York: Columbia University Press, 2013, 54.

materialized from the multi-community study named Atherosclerosis in Communities (ARIC), in Jackson Mississippi. The ARIC study had 5,302 “self-identified” African American patients between the ages of 35–84 years old.²³² The JHS patients’ information was embedded in a genetic collection for future study. JHS’ patients came from a participant lottery, the ARIC program and volunteers from the Jackson, Mississippi area.

JHS’s goal was to illustrate similarities of blacks and whites and discredit the naïve notion that only blacks get hypertension and are immune to cardiovascular disease. JHS, also known as the “Black Framingham,” did not want to create a medical narrative that African Americans were biologically different from other racial groups, but wanted to break the racial glass ceiling in clinical research asserting African Americans are viable human beings capable of representing humanity. JHS set the precedence for minority inclusion for serious consideration in quantitative analysis in clinical research, which influenced the passing of the National Institutes of Health (NIH) Revitalization Act of 1993 which required, “federally funded clinical trials include women and ethnic minorities as subjects and disaggregate statistics by gender and ethnicity.”²³³ Before the development of JHS, the city of Jackson’s ARIC program represented the largest historical effort to recruit African Americans in clinical research.²³⁴ JHS results show important factors like socioeconomic status and psychosocial elements profoundly impact African Americans’ heart health. JHS’s findings urged a medical solidarity for

²³² Fuqua, Sonja R., et al. “Recruiting African-American research participation in the Jackson Heart Study: methods, response rates, and sample description.” *Ethn Dis.* 15, no. 4 Suppl 6 (2005): S6-18.

²³³ Briggs, Charles L. “Communicability, Racial Discourse, and Disease.” *Annual Review of Anthropology.* 2005, Vol. 34 Issue 1, 280.

²³⁴ Fuqua, “Recruiting African-American research participation,” S6-18.

cardiovascular disease in the African American community. The development of a race-based drug was constructed to be the solution.

BiDil's Beginnings

In 1989, V-HeFT's lead cardiologist and University of Minnesota professor, John Cohn received a non-racial patent of the H/I combination improving heart treatments. In 1992, BiDil ("Bi" meaning two and "Dil" meaning dilators), the H/I combination into one pill, was filed as a new drug. In 1995, Medco (pharmacy benefit manager "PBM" who process and pay drug claims) received patent rights from Cohn and trademarked BiDil. In 1996, Medco attempted to get the Food & Drug Administration's (FDA) approval for BiDil which was denied, in a nine to three decision, due to unclear data in V-HeFT trial. The V-HeFT trials' data did not meet regulatory statistical standards to establish efficacy for the new drug. The FDA asserted, "V-HeFT I and II trials had to be stopped prematurely due to funding problems. They therefore did not have sufficient power for their planned [statistical] analyses."²³⁵ Medco gave up the patent process and returned the intellectual property rights of BiDil to Cohn.

After BiDil's first rejection by the FDA, Cohn analyzed data by race. Cohn used old data from the V-HeFT I and II trials which compared 395 African Americans with 1,024 whites. The only remote racial difference shown was in the V-Heft I trial with only 49 African Americans taking the H/I combination. According to Cohn, "The H/I combination appears to be particularly effective in prolonging survival in black patients and is as effective as enalapril in this subgroup. In contrast, enalapril shows its more

²³⁵ Kahn, *Race in a Bottle*, 56.

favorable effect on survival, particularly in the white population.”²³⁶ Cohn’s findings was published in an article “Racial Differences in Response to Therapy for Heart Failure: Analysis of the Vasodilator-Heart Failure Trials,”²³⁷ asserting BiDil functions better in African Americans compared to whites. The article was a key influence in the FDA’s approval.

The article said racial groups might have different reactions to drugs. Cohn and Carson asserted a specific drug had the probability to react in different ways among racial groups. The article laid the foundation for using BiDil as a drug treatment for heart failure in African Americans. The momentum of the article caused Cohn to relicense BiDil and give the production rights to NitroMed. NitroMed licensed the same H/I combination for a non-race-specific patent from 1987 to 2007 and an African American patent from 2000 to 2020. NitroMed continued to gain momentum for BiDil and raised over \$30 million to start their African-American Heart Failure Trial (A-HeFT).²³⁸

FDA’s Approval

In the A-HeFT trial (2004), follow-up was planned for 18 months 1,050 “self-identified African-Americans” were subjects. NitroMed’s Data Safety Monitoring Board stopped the A-HeFT trial because of the discovery that “BiDil reduced mortality rates by some 43%,”²³⁹ which NitroMed felt was a sufficient percentage. In June 2005, the FDA approved BiDil as a drug to treat African Americans with heart failure. BiDil made

²³⁶ Kahn, *Race in a Bottle*, 59.

²³⁷ Ibid.

²³⁸ Kahn, “Exploiting Race,” 739.

²³⁹ Ibid.

history as the first race-based drug. The FDA had four justifications for approving BiDil.

The FDA asserted,

(1) Data from 3 clinical trials showed dramatic effectiveness of hydralazine hydrochloride and isosorbide dinitrate in black patients and supported a differential effect in black and white patients. (2) Not understanding the reasons for the difference in treatment effect by race did not justify withholding the treatment from those who could benefit from it. (3) Regulatory and other concerns associated with drug approval for narrow patient populations did not justify withholding BiDil from those who could benefit from it. (4) Race and other demographic characteristics have long been important to consider in analysis of trials and as a matter of equity and justice.²⁴⁰

In the FDA's perception, these reasons justified the approval of BiDil as an important element in the alleviation of heart failure in the African American population. However, the FDA did not ignore the inconsistencies of NitroMed's clinical trials.

FDA's Justifications

The FDA's first justification for approving BiDil created controversy because its clinical trials had no other racial populations to compare results to, which left BiDil's African American efficacy uncertain. The FDA asserted, "Data from 3 clinical trials showed dramatic effectiveness of hydralazine hydrochloride and isosorbide dinitrate in black patients and supported a differential effect in black and white patients."²⁴¹ H/I for decades have helped black and white patients with heart failure and cardiovascular disease. FDA's affirmation that H/I had a better effect on African Americans than on whites suggests skewed research. The FDA's conclusion was not based on conclusive evidence that BiDil had a unique level of efficacy on African Americans, as opposed to

²⁴⁰ Temple, Robert., and Stockbridge, Norman L.. "BiDil for Heart Failure in Black Patients: The U.S. Food and Drug Administration Perspective." *Annals of Internal Medicine*. 146, no. 1 (January 2, 2007), 57-59.

²⁴¹ *Ibid.*, 57.

other racial ethnic groups, but on post hoc analyses of the two 1980s H/I trials with the general population. The FDA did not consider earlier H/I trials a sufficient basis for approval. Ironically, the FDA continued research as a “good case” for African American heart failure research.

The purpose of clinical research is to assess all likely combinations of groups to determine where significant differences are located. Clinical research uses clinical trials processes to examine group comparisons. The comparison process used in the BiDil clinical trials was the post hoc comparison. Post hoc groups are broken into three or more groups called subgroups. Subgroups are used to compare research findings, which was not the case with BiDil. Dr. Kirsten Bibbins-Domingo, endowed chair in medicine and professor of medicine and of epidemiology and biostatistics at the University of California, San Francisco (UCSF) and Dr. Alicia Fernandez, Professor of Clinical Medicine at UCSF, assert, “In general, post-hoc subgroup analyses should be interpreted with caution and should be used primarily for generating hypothesis- not for determining policy, which appears to be the case here.”²⁴² A sufficient amount of participants are rare in each subgroup, which makes research difficult to satisfy sample sizes needed for accurate evaluations. Multiple post hoc subgroup analyses increase the risk of generating statistically significant and random group differences. Multiple subgroups can affect missing differences in data. Post hoc subgroups analyses are not a part of the original trial design.

Patients in subgroups are randomly allocated to intervention and control groups. Race and medicine expert Jonathan Kahn states, “The post hoc subgroup analyses of V-

²⁴² Kahn, *Race in a Bottle*, 93.

HeFT I and II suffer from the same potential problems as those faced by all post hoc subgroup analyses of randomized controlled trials: a loss of statistical power and the potential for covariate imbalances.”²⁴³ The data out of BiDil’s clinical trials were based on unclear post hoc data. The FDA’s denial to Medco was evidence that Medco and Cohn’s use of post hoc subgroups had vague and non-efficacious data.

NitroMed’s clinical trials omitted mortality rates of senior citizens who have heart failure. NitroMed’s age-focused interpretation obscures BiDil’s data being effective in African Americans. In clinical trials, the misinterpretation and omission of data does not produce legitimate results. NitroMed used data from the 1981 National Center for Health Statistics, which described a black-to-white ratio of heart failure mortality (2:1).²⁴⁴ In 1995, the Centers for Disease Control (CDC) stated patients 65 and older, with mortality rates from heart failure nearly equal for blacks and whites (a 1.1:1 ratio), were not included in NitroMed’s data.²⁴⁵ Ninety four percent of all heart failure mortality occurs over 65 years old. NitroMed had a distorted focus on data concentrating only on “patients aged from 45 to 64 years, thus boosting the black to white differential.”²⁴⁶ The interpretation of data suggests BiDil’s effectiveness on African Americans resulted in the African Americans studied were prone to die from heart disease at a younger age.

African American subjects were the only trial group enrolled into the A-HeFT trial study. The absence of other racial populations in A-HeFT trial indicate BiDil should not have been presented and approved as a legitimate claim of differential efficacy based

²⁴³ Kahn, Jonathan D., et al. “Flaws in the U.S. Food and Drug Administration's Rationale for Supporting the Development and Approval of BiDil as a Treatment for Heart Failure Only in Black Patients.” *Journal of Law, Medicine & Ethics* 36, no. 3 (Fall 2008), 450.

²⁴⁴ Kahn, *Race in a Bottle*, 72-78.

²⁴⁵ Ibid.

²⁴⁶ “Illuminating BiDil.” *Nature Biotechnology*, Vol. 23 Issue 8 August 2005, 903.

on race. In contrast, there were numerous drugs being tested in white populations but no urgency to call these “Caucasian” or “European American” drugs. NitroMed was not being consistent in their vision of race-based medicine. Drugs being tested in all races would be attributed to specific races. Yet, race-based medicine was attributed only to Blacks or African Americans, which ignores other “racial” illnesses in other groups like Tay Sachs in Jews and Cystic Fibrosis in whites. NitroMed’s concentration of African Americans suggests a financial attempt to capitalize on a specific racial group.

Race as Biocapital

NitroMed’s approval, trials, and construction of BiDil illustrates biocapitalistic motives. The notion of biocapital is, “the circuits of land, labor, and value (in a classic Marxian sense) that are inhabited by biotechnology innovation and drug development; on the other hand, as the increasingly constitutive fact of biopolitics in processes of global capitalism.”²⁴⁷ In other words, biocapital is an idea of multiple modern systems of capitalism with emerging sciences and technologies in life sciences (i.e. zoology, botany, microbiology, biology, biochemistry and physiology). In relation to BiDil, the biocapital element is race. NitroMed’s role in biocapital creates alienation and expropriation that has been constructed on a particular notion of race, to express an innovative technique for pharmacology and biotechnology. Similar to commercial capitalism, race conjoined with biocapitalism is speculative; based on conjecture rather than knowledge. Race as biocapital influences medicalization and biomedicalization in racial groups.

²⁴⁷ Sunder Rajan, Kaushik. *Biocapital: The Constitution of Postgenomic Life*. Durham: Duke University Press, 2006, 78.

Congestive heart failure produces 400,000 to 700,000 new cases per year with 750,000 African Americans out of 5 million Americans already affected, an estimate profit of \$40 billion dollars annually.²⁴⁸ NitroMed did not want inclusive participation of racial groups to happen because the non-racial patent will expire in 2007 but the African American race-specific patent will expire in 2020, which will give “NitroMed an additional 13 years of market monopoly protection”²⁴⁹ compared to only two years for the non-race-based patent. NitroMed had better financial incentive marketing BiDil as an African American tailored medicine, which denotes racial targeting as their sales approach.

In 2005, it could take up to fifteen years to bring a drug to market costing an estimated price between \$700 and \$900 million and around \$1.2 billion in 2010.²⁵⁰ Yet, NitroMed cheated the drug development process. NitroMed only paid \$43 million and brought BiDil to the market in five years by exploiting its race-based advantage.²⁵¹ A very unorthodox process for a drug which main ingredients H/I had been used as a non-racial “off label” prescription since the 1980s. The FDA’s “off label” description states,

The drug label of FDA-approved drugs gives information about the drug, including the approved doses and how it's to be given to treat the medical condition for which it was approved. When a drug is used in a way that is different from that described in the FDA-approved drug label, it is said to be an “off-label” use. This can mean that the drug is:

- Used for a different disease or medical condition.
- Given in a different way (such as by a different route).
- Given in a different dose.

For example, when a chemotherapy drug is approved for treating one type of cancer, but is used to treat a different cancer, it is off-label use. Off-label is also

²⁴⁸ Kahn, *Race in a Bottle*, 50.

²⁴⁹ Kahn, “Exploiting Race,” 739.

²⁵⁰ Kahn, *Race in a Bottle*, 88.

²⁵¹ *Ibid.*, 92.

called “non-approved” or “unapproved” use of a drug. New uses for these drugs may have been found, and often medical evidence supports the new use. But the makers of the drugs have not put them through the formal, lengthy, and often costly studies required by FDA to officially approve the drug for new uses.²⁵²

The “off label” H/I combination was so effective in the general population that the American Heart Association endorsed it as an adequate treatment for heart failure for over fifteen years.

The “off label” H/I combination was a cheaper alternative for patients of all races that had heart failure issues but did not have the financial means to obtain a prescription. African Americans are one of the main groups struggling economically. The average black household has less than one-tenth of the wealth of a typical white household²⁵³ and the average white household has 16 times the wealth of the average black household.²⁵⁴ NitroMed asserted the reason they made BiDil was to close the health disparity gap for African Americans dealing with heart failure.²⁵⁵ It was logical and consistent with their claim to make BiDil affordable to such a disenfranchised group. Unfortunately, NitroMed’s biocapitalistic motive superseded their pseudo-health equity initiative and focused on market based goals.

NitroMed speculated the perceived innovation of BiDil will bring in a substantial amount of money. As Sunder states, “Biocaptial is the articulation of a technoscientific

²⁵² FDA. “Understanding Investigational Drugs and Off Label Use of Approved Drugs.” Last modified June 24, 2015. <http://www.fda.gov/ForPatients/Other/OffLabel/default.htm>

²⁵³ Luhby, Tami. “5 Disturbing stats on black-white inequality.” *CNN*. August 21, 2014. Accessed on July 18, 2015. <http://money.cnn.com/2014/08/21/news/economy/black-white-inequality/>

²⁵⁴ Shin, Laura. “The Racial Wealth Gap: Why A Typical White Household Has 16 Times The Wealth Of A Black One.” *FORBES*, March 26, 2015. Accessed on July 18, 2015 <http://www.forbes.com/sites/laurashin/2015/03/26/the-racial-wealth-gap-why-a-typical-white-household-has-16-times-the-wealth-of-a-black-one/>

²⁵⁵ Kahn, *Race in a Bottle*, 216.

regime ... over determined by the market.”²⁵⁶ Life sciences expedite the production of cutting edge technologies and therapeutic interventions. The results of such innovative technologies and interventions are ambiguous in nature. Regardless of the knowledge of these innovations, the market inputs the value of proposed technologies and interventions with intent to calculate their value and return on investments. NitroMed is a key example of the biocapitalistic process expediting the process of BiDil, which caused huge speculation in the stock market.

In 2004, a week after the A-HeFT trial completion, NitroMed’s stock tripled from \$6.90 per share to over \$21 per share. In 2005, NitroMed stock went up to \$29 per share after FDA approval. On June 27th, four days after BiDil’s FDA approval, NitroMed set the cost to BiDil at \$1.80 per pill, with a standard dose of six pills per day, totaling \$10.80 per day.²⁵⁷ BiDil cost three times more than Coreg (beta-blocker) \$3.56 per day and seven times more than the \$0.25 cents per pill “off label” H/I combination. BiDil’s financial gain for NitroMed was set. NitroMed’s next step was to appeal to the African American community through key partnerships.

NitroMed’s key partnerships were with ABC, the National Minority Health Month Foundation (NMHMF), and U.S. Representative Donna Christensen (D-Virgin Islands). Before the FDA approval meeting of BiDil, the NMHMF held a joint press conference with prominent African American public health groups like the Alliance of Minority Medical Associations, the ABC, the International Society on Hypertension in Blacks, the National Association for the Advancement of Colored People (NAACP), and

²⁵⁶ Sunder, *Biocapital*, 111.

²⁵⁷ Kahn, *Race in a Bottle*, 103-104.

the National Medical Association urging the FDA to approve BiDil.²⁵⁸ Specifically, the National Medical Association supported BiDil.²⁵⁹ These groups argued that BiDil finally brought personalized medicine to the African American community. In contrast, not all African American health organizations were quick to jump on the BiDil band wagon.

The Alliance of the Minority Medical Associations' President Randall W. Maxey stated, "The assertion that this is a race drug is misguided."²⁶⁰ Maxey strongly urged the FDA not to approve BiDil. One would think that the massive contradictions, uncertainties, and inconsistencies of BiDil's clinical process would influence key groups in African American public health to reject BiDil. Unfortunately, there was conflict of interest. NitroMed knew their success would not be legitimate without the backing of key players in the African American public health community. NitroMed could not offer sound clinical data but they could offer compensation to promote their product. NitroMed contributed \$200,000 to the ABC, \$14,000 to U.S. Representative Christensen, and an unrestricted educational grant to the NMHMF.²⁶¹ In support of NitroMed, Congresswoman Christensen said, "BiDil can save thousands of lives and reduce untold suffering for African American heart failure patients and their families."²⁶² Also, NitroMed gave the NAACP \$1.5 million dollars.²⁶³ The African American public health groups endorsements and BiDil's "innovation" to alleviate health disparities in communities of color (fueled by biocapital anticipations) was enough for BiDil's

²⁵⁸ Kahn, *Race in a Bottle*, 101.

²⁵⁹ Briggs, "Communicability, Racial Discourse, and Disease," 281.

²⁶⁰ Kahn, *Race in a Bottle*, 101.

²⁶¹ Ibid.

²⁶² Inda, Jonathan Xavier. "For Blacks Only: Pharmaceuticals, Genetics, and the Racial Politics of Life." *Materiali Foucaultiani*. vol. I, n. 2 2012, 108.

²⁶³ Bell, Susan E., and Anne E. *Reimagining (Bio)Medicalization, Pharmaceuticals and Genetics: Old Critiques and New Engagements*. 2015, 182.

approval. Yet, ironically, a pill exclusively made for African Americans was too expensive for the group it was supposed to benefit.

A year after BiDil's release in the stock market, its stock value fell from \$27.00 per share to \$2.50 per share.²⁶⁴ BiDil's lack of financial credibility is not surprising. When marketing a prescription product to the consumer-patient the two important factors are efficacy and affordability, which BiDil provided neither. The Veterans Health Administration (VHA) denied Tier 2 status to BiDil and criticized its cost effectiveness asserting, "The annual cost of BiDil would range from \$1,382 to \$2,765 per patient, while the annual cost of comparable generics would range from \$45 to \$63 per patient."²⁶⁵ The VHA's evaluation of BiDil led them to conclude lower priced generics would save hospitals more money compared to using BiDil. Consequently, the entire ABC group did not recommend BiDil. Dr. Charles Curry, Head Cardiologist at Howard University and founding member of ABC, criticized BiDil's cost and wanted "practical doctors using generics instead."²⁶⁶ ABC realized that the cost of BiDil did not make practical financial sense. The socially incompetent cost projection of BiDil led to its financial failing. Furthermore, the pricing of BiDil did not encourage physicians to prescribe it to their patients.

Most of the time physicians have their patients' best interests at heart. Many physicians were not comfortable integrating BiDil within their practices for three reasons: price, compliance, and veracity (truthfulness or truth-telling). In a study by the *Journal of General Internal Medicine*, "Physicians overwhelmingly voiced concern that commercial

²⁶⁴ Pollock, *Medicating Race*, 165.

²⁶⁵ Kahn, *Race in a Bottle*, 117.

²⁶⁶ Pollock, *Medicating Race*, 167.

considerations shaped the development of BiDil and expressed dismay at what they perceived to be the primary aim of race-specific pharmaceutical trials, namely to get physicians' attention for marketing purposes."²⁶⁷ NitroMed's reimbursement incentives was not favored by many doctors. It was not practical to use BiDil when other affordable options were available for their patients. Also, BiDil's regiment of consumption three times per day compromises the physician's responsibility for beneficence (doing good) and nonmaleficence (doing no harm) if the patient is already taking other drugs. BiDil may create issues of compliance in physicians' medical practices by fatal drug reactions that can produce unwanted comorbidities.

Physicians should value their patients trust. In BiDil's case, physicians should be even more sensitive to African Americans because of the group's egregious American medical history. Incorporating BiDil into the medical practice is a step backward because it medically "pimps" the African American community by doctors prescribing it. NitroMed's poor marketing and lack of physician support resulted in an unsuccessful attempt for race-based medicine. In 2009, Deerfield Capital acquired NitroMed for \$36 million and planned to develop a more potent form of BiDil that can be taken once a day compared to three times a day and NicOx S.A. purchased NitroMed's unlicensed patents covering nitric oxide-donating compounds.²⁶⁸ In 2012, Deerfield Capital Management sold the rights to BiDil to Arbor Pharmaceuticals, Inc. of Atlanta, Georgia.²⁶⁹ Despite BiDil's unscientific prowess and reputation, Arbor Pharmaceuticals is capitalizing from

²⁶⁷ Kahn, *Race in a Bottle*, 120.

²⁶⁸ Krinsky, Sheldon. "The art of medicine: The short life of a race drug." *Lancet*. 379, no. 9811 (January 14, 2012), 115.

²⁶⁹ Hawkins-Taylor, Chamika, and Angeline M. Carlson. "Communication Strategies Must Be Tailored to a Medication's Targeted Population: Lessons from the Case of BiDil." *American Health & Drug Benefits*. 6, no. 7 (2013) 408.

BiDil and are “planning to do further research to try to predict more accurately which patients are most likely to respond to the treatment.”²⁷⁰ BiDil is still going strong in the drug market sustaining misunderstandings of race and disease.

NitroMed’s construction of BiDil regurgitated the eugenic idea that race is a proxy for disease. As Johnathan Kahn profoundly asserts, “NitroMed put a ‘black face’ on BiDil as it went before the FDA for race-specific approval.”²⁷¹ NitroMed medicalized race and it is attributing the pathology of heart failure to African Americans, which is historically and scientifically false. The biocapitalistic use of BiDil has medicalized and biomedicalized race in the twenty first century.

Race: Medicalization and Biomedicalization

The FDA’s second justification for approving BiDil was an ethical concern toward racial difference. The FDA asserted, “Not understanding the reasons for the difference in treatment effect by race did not justify withholding the treatment from those who could benefit from it.”²⁷² The FDA believed withholding BiDil from those who might benefit was not necessary and irresponsible. The FDA did not wait for a full understanding of how the drug worked. The FDA was irresponsible to expedite a drug when they did not have a clear understanding of its risks and benefits. Responsible pharmaceutical research requires time to properly assess the risks and benefits within a population, especially dealing with the complexities of race and socioeconomics. In regards to BiDil, the African American population should not be the exception for hurried research practices.

²⁷⁰ Downey, Laurence J. “BiDil: alive and kicking.” *Lancet*. 379, no. 9829 (May 19, 2012), 1876.

²⁷¹ Kahn, *Race in a Bottle*, 102.

²⁷² Temple, “BiDil for Heart Failure in Black Patients,” 58-59.

FDA's undeveloped allegation that BiDil is a race-based drug while simultaneously stating they lack the full understanding of how the drug works is poor science and judgment. The FDA's urgency to get BiDil in the drug market was internally induced and created the illusion that BiDil was this miracle vaccine for African Americans with heart issues. The FDA's statement is disingenuous and raises concern about FDA's upholding of the 1906 Food and Drug Act on drug approval and the 1962 Amendments.

The Food and Drug Act established precedent for regulation of medication by enforcing medicine, safety, efficacy, and prosecuted false drug claims. The Food and Drug Act, "Prevented the manufacture, sale, or transportation of misbranded, poisonous, or deleterious drugs and medicines."²⁷³ The Act had unclear guidelines for compliance, which was mediated by the FFDC Act and the 1962 Amendments. The FFDC Act, "provided consumer protection by requiring scientific proof of the safety of new products, regulating therapeutic devices, making the prosecution of false drug claims easier, and raising the penalty of violators."²⁷⁴ The 1962 Amendments set the precedence for drug efficacy and required:

That adverse reactions of drugs be reported to the Food and Drug Administration, that risks and benefits of drugs accompany medical journal advertisements of drugs, *and that the effectiveness, as well as the safety, of a drug be proven before it is marketed (Emphasis added).*²⁷⁵

The FDA's approval of BiDil shows medicalization's effect on compliance in regard to consumer protection and efficacy.

²⁷³ Zarcadoolas, Christina., et al. *Advancing Health Literacy: A Framework for Understanding and Action*. Jossey-Bass; 1 edition (June 5, 2006), 26.

²⁷⁴ Ibid., 26-27.

²⁷⁵ Ibid.

In 1972, Irving Zola framed the concept of medicalization as a precursor of the growing dominance of medicine's influence in jurisdiction, authority, and practice in society.²⁷⁶ Prescribed medications for most of the twentieth century were used as a secondary option for the patient's therapeutic intervention. However, there was a huge shift beginning in the 1980s.

The rise of 'Direct-to-consumer' (DTC) marketing brought a new level of awareness about medical interventions to the American consumer but the marketing was limited. Pharmaceutical companies could only place drug advertisements in popular magazines and newspapers. DTC marketing on drugs intensified in the 1990s with the passing of the Food and Drug Administration Modernization Act of 1997 which "loosened the restrictions placed on the kind of information that pharmaceutical companies could share with physicians regarding 'off label' uses of their drugs."²⁷⁷ The Act influenced the approval of Paxil (paroxetine hydrochloride) for the treatment of depression with Prozac and other drugs (SSRIs) to follow. "Medicalization" quickly became dominant in mainstream American culture.

Medicalization is the process when nonmedical issues become interpreted, defined, and treated as medical problems, usually labelled as a certain illness or disorder. Medicalization simply means "to make medical."²⁷⁸ Regular life events like menstruation, birth control, infertility, impotency, childbirth, menopause, aging, and death are now medicalized. As a result, patients are transformed into consumers and are

²⁷⁶ Clarke, Adele. *Biomedicalization: Technoscience, Health, and Illness in the U.S.* Durham, NC: Duke University Press, 2010, 20.

²⁷⁷ Conrad, Peter. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders.* Baltimore: Johns Hopkins University Press, 2007, 17.

²⁷⁸ *Ibid.*, 4.

less tolerant dealing with the symptoms of life events (i.e. Viagra for men and women). Instead of the patients going through longer processes of healing, medicalization produced a “microwave” mentality in patients. Patients have an uncomfortable symptom. The therapeutic intervention was simply pop a pill or injection that will alleviate the symptom(s) quickly. A recent example of medicalization is the drug injection called Kybella (deoxycholic acid) made by Kythera Biopharmaceuticals in Westlake Village, California, which dissolves chin fat (double chin).²⁷⁹ Medicalization promoted the prescription drug from a secondary medical intervention to a primary means in clinical practice, which meshed the pharmaceutical companies and patients in a significant relationship co-dependent of each other.

Medicalization changed the paternal model of doctoring. Patients became consumers and empowered to seek out medical interventions and services they desired with or without the doctor’s approval. The traditional patient-physician power dynamics changed because if your doctor does not agree with you taking a prescription of personal interest or does not want to do a procedure, you can find a doctor that will comply with your desires. Medicalization engages life itself through the pursuit of enhancements to alleviate individuals’ physiological inconsistencies and anxieties through medical forms of interventions.

The FDA’s Modernization Act of 1997 opened the “Pandora’s Box” of drug and medical marketing. Medicalization has created an oversaturation of drugs in the market, which has affected the non-maleficence of the patient. According to the *Journal of the*

²⁷⁹ Food & Drug Administration. “FDA approves treatment for fat below the chin.” *FDA*, April 29. Accessed on April 29, 2015.
<http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm444978.htm>

American Medical Association March 2015 article, drug overdose deaths (by opiate pain and other medications) have been rising since the early 1990s and is the leading cause of injury death in the United States.²⁸⁰ Due to the overwhelming access of drugs, the risks are greater compared to ten or fifteen years ago and side effects caused by medication generate countless risks. Regardless of the rise of alternative and homeopathic medicine, medicalization has ingrained a culture of medication as the main form of therapeutic intervention.

Medicalization's fallacy narrowly focuses on the source of the problem in the individual rather than including the social environment and calls for medical interventions not social solutions. Also, medicalization has its limitations because medical phenomena are intangible. For example, masturbation, hysteria, homosexuality, and drinking coffee²⁸¹ were deemed as medical issues but views changed overtime. Likewise, race is a concept that changes overtime. The approval of BiDil re-medicalized race within medicine through revived unorthodox eugenic ideologies in the FDA's approval meeting on BiDil.

As discussed, the racial research component of BiDil did come from John Cohn but the racial medical language came from Robert Nissen, chair of the FDA Advisory Committee. After the FDA reviewed BiDil, Nissen asserted, "We're using self-identified race as a surrogate for genetic markers. It is very unusual; it is precedent-setting... But it is the case that we are moving forward to genome-based medicine. It's going to

²⁸⁰ Haffajee R.L., Jena A.B., Weiner S.G. Mandatory use of prescription drug monitoring programs. *JAMA - Journal of the American Medical Association*. Volume 313, Issue 9, 3 March 2015, 891-892.

²⁸¹ LaMotte, Sandee. "Health effects of coffee: Where do we stand?" *CNN*, August 14, 2015. Accessed on August, 16, 2015. <http://www.cnn.com/2015/08/14/health/coffee-health/index.html>

happen.”²⁸² Nissen ignored the overwhelming data inconsistencies of the V-HeFT and A-HeFT trials and focused on racial difference as the only justification for BiDil’s approval.

Nissen erroneously compared heart failure to orphan disease. Orphan disease consists of diseases like Hamburger disease, Lou Gehrig's disease, Job syndrome, cystic fibrosis, gigantism (acromegaly) and Tourette's syndrome. Orphan disease effects less than 200,000 people compared to 750,000 African Americans who suffered from heart failure in the United States.²⁸³ Nissen’s sample sizes were inconsistent because one cannot compare a disease that affects a general population group (Orphan Disease) to a racial group (Heart Failure). There is no scientific basis to use such an example as rationale and justification to approve BiDil.

Similar to FHS, BiDil’s objectives were revised after data collections. Also, Nissen’s interpretations skewed information to reflect a preferred result, which in BiDil’s case was race.²⁸⁴ As Jonathan Kahn states, “It was race itself that he connected to disease, people suffering from ‘African-American-ness’ deserved the same special consideration as those suffering from an orphan disease.”²⁸⁵ Nissen’s assertion reifies race as a biological truth that supersedes statistics, which led to the FDA’s justification that race is a proxy for disease. Furthermore, the FDA biomedicalized (social processes are assigned meaning) race by approving BiDil as a form of enhancing personalized medicine for African Americans.

²⁸² Kahn, *Race in a Bottle*, 89.

²⁸³ Ibid., 98.

²⁸⁴ Shim, Janet K. *Heart-Sick: The Politics of Risk, Inequality, and Heart Disease*. NYU Press, 2014, 55.

²⁸⁵ Kahn, *Race in a Bottle*, 98.

Biomedicalization practices, “emphasize transformations of such medical phenomena and of bodies, largely through sooner-rather-than-later technoscientific interventions not only for treatment but also increasingly for enhancement.”²⁸⁶

Technoscience produce identity through applying science and technology to our bodies. Technoscience creates identities and labels exemplified in BiDiI’s case two ways. It imposes new mandates and performances that become incorporated into one’s sense of self and creates new categories of health related identities and redefines old ones.²⁸⁷

Biomedicalization courts fatalism to create a mindset of vulnerability due to risk factors and self-surveillance. Risk factors and self-surveillance are components of the medical gaze, which is the dehumanizing medical separation of the patient’s body and personhood. Risk factors and self-surveillance construct the spaces, technologies, discourses, and processes of biomedicalization. These social constructions inject interventions around the risk and chronic diseases. Symptoms are obsolete due to,

The ‘problematization of the normal’ and the rise of what Armstrong (1995) calls ‘surveillance medicine,’ everyone is implicated in the process of being ill. Both individually and collectively, we inhabit tenuous and liminal spaces between illness and health, leading to the emergence of the ‘worried well,’ rendering us ready subjects for health-related discourses, commodities, services, procedures, and technologies.²⁸⁸

Similarly, race-based medicine affects minority communities’ overall understanding of health through communicating false notions that external traits of minorities contribute to the cause of disease.

²⁸⁶ Clarke, *Biomedicalization*, 2.

²⁸⁷ *Ibid.*, 81.

²⁸⁸ *Ibid.*, 64.

Race, understood to generalize a group of people who have similar physical and genetically coded traits, should not be used to determine the development of drugs. There are many causes of disease like poor nutrition, lack of exercise, poor hygiene, heredity, and environmental factors. Race-based medicine accentuates a false fatalistic ideology that one's personal health habits are not significant for disease prevention compared to one's external racial traits.

NitroMed's implications through the biomedicalization of risk factors and self-surveillance related to BiDil recreated the eugenic stratification of racial bodies as biologically different. Such markers impose sociobiological and sociocultural perceptions that rationalize, "'different' kinds of bodies and the ways in which individuals so marked think about themselves and their health."²⁸⁹ NitroMed's racial construction of BiDil was to project a familiar urgent fatalism to African Americans that have heart failure. The premise was that you are black, you are different, so take this drug that was specifically made for "people like you." Consequently, race and biomedicalization intersect with geneticization. Geneticization is a social process and genetic form of medicalization that centers genes as the core of interpreting meaning and genetic findings supersede historical sociological explanations.²⁹⁰

Genetics and Race

The FDA's third justification for approving BiDil is, "Regulatory and other concerns associated with drug approval for narrow patient populations did not justify

²⁸⁹ Clarke, *Biomedicalization*, 220.

²⁹⁰ Bell, *Reimagining (Bio)Medicalization*, 176.

withholding BiDil from those who could benefit from it.”²⁹¹ The FDA’s problematic justification naively overlooks the stigmatization of African Americans’ heart failure. Stigmatization is the label or mark of disgrace toward a person or a group. The FDA approving BiDil stigmatizes African Americans by attributing and associating heart failure and unhealthy behavioral traits with African Americans. The perception of race-based medicine misconstrues the distinctions of race, ancestry and genetics by promoting assumptions that race alone is the only marker of disease. Clinical research of minorities needs to have a precedent, Robert Temple and Norman L. Stockbridge assert, “evidence of a genetic basis for a racial distinction must clearly be shown before a race-specific approval, even in the face of compelling benefit in one race.”²⁹² The FDA does not recognize the stigmatizing of race as a concern. Cultural competency in research and patient care is a fundamental trait, which the FDA’s approval of BiDil disregards.

Since 1950, the United Nations Educational, Scientific & Cultural Organization (UNESCO), the American Association of Physical Anthropologists, the International Union of Anthropological & Ethnological Sciences, the American Sociological Association, and the American Anthropological Association all agreed that race is not a proxy for biological explanations and difference.²⁹³ Yet, the concept of race as an explanation for disease is still infiltrating science and medicine in the twenty first century.

²⁹¹ Temple, *"BiDil for Heart Failure in Black Patients,"* 58-59.

²⁹² *Ibid.*, 61.

²⁹³ Bliss, Catherine. *Race Decoded: The Genomic Fight for Social Justice*. Stanford, California: Stanford University Press, 2012, 3.

The previously named institutions have contributed to great progress on how we should view race in science and medicine. However, their bold statements do not erase the ingrained societal effects of racial ideologies in American society. Mentioned in chapter one, The United States Office of Management and Budget (OMB) constructed racial and ethnic categories used to collect, organize, and analyze the country's demographic data. Such information is collected through the census forms filled out periodically. OMB changed racial categories at least ten times since its inception in 1800.²⁹⁴ For example, the first US Census listed,

Free White Male, Free White Female, Other Free Person, and Slave. During the nineteenth century, additional categories that fell in and out of use included Free Colored Person, Black, Mulatto, Quadroon, Octoroon, Indian, Chinese, and Japanese. The twentieth century saw a new proliferation of categories including Hindu, Korean, and Negro.²⁹⁵

On May 12, 1977, the OMB's Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting was produced to provide,

Standard classifications for record keeping, collection, and presentation of data on race and ethnicity in Federal program administrative reporting and statistical activities. These classifications should not be interpreted as being scientific or anthropological in nature, nor should they be viewed as determinants of eligibility for participation in any Federal program. They have been developed in response to needs expressed by both the executive branch and the Congress to provide for the collection and use of compatible, nonduplicated, exchangeable racial and ethnic data by Federal agencies.²⁹⁶

After many changes, this process of taxonomy (classification) led to the categories of race and ethnicity we know today like: American Indian or Alaska Native, Asian, Black

²⁹⁴ Wailoo, et al., *Genetics and the Unsettled Past*, 52.

²⁹⁵ Kahn, *Race in a Bottle*, 28.

²⁹⁶ CDC. "Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting." CDC, May 12, 1977. Accessed on August 20, 2015. <http://wonder.cdc.gov/wonder/help/populations/bridged-race/directive15.html>

or African American, Native Hawaiian or Other Pacific Islander, with Hispanic or Latino and Not Hispanic or Latino as the two categories for ethnicity.²⁹⁷ The OMB's categories are used on the local, state, and federal levels for research, data, and practice, which are used for public health issues and biomedical research.

The United States Patent and Trademark Office (PTO) have powerful influence through federal officials controlling the use of race into biomedicine. The PTO's decisions produce constructed racial categories used for the U.S. Census. The racial categories are used as a means for biological research that support the appropriation of race and biology in biomedicine. Genetic research has rapidly grown since the completion of the Human Genome Project (HGP) in 2003. HGP was an international research effort to sequence and map all of the genes of humanity, known as the genome. The mass amount of data and knowledge that had been obtained was tremendous. Such knowledge needs to be collected, stored, and classified as genetic information. The OMB and PTO racial categories are used in international biobanks. Hence, international federal governments sponsored data banks to maintain genetic data for biomedical researchers.

The databases are the National Institute of General Medical Sciences (NIGMS) under the Department of Coriell Human Genetic Variation Collections, the DNA Polymorphism Discovery Resource (PDR), the database of single-nucleotide polymorphisms (dbSNP database), the Haplotype Map Project (IHMP or HapMap), the National Center for Biotechnology Information (NCBI or GenBank), the DNA DataBank of Japan (DDBJ), and the European Molecular Biology Laboratory (EMBL).²⁹⁸ These

²⁹⁷ Kahn, *Race in a Bottle*, 28.

²⁹⁸ *Ibid.*, 30.

databases have unprecedented power affecting how genetic information is used. Researchers use these databases to organize racial categories, genetic information, and apply genetic data by race classification. For example, the PDR's chief scientists, who were from the HGP, created race-based sample sets by federal race classification.²⁹⁹

Biobanks romanticized race with biomedicalization through the use of classification. Classification is the assignment of organisms to groups within a system of categories distinguished by structure and origin. It implies class, order, and phylum (race, stock, or kind) of individuals and groups. Classification is defined by ethical choices that bring meaning and identification. Classification inevitably exclude an individual or group as “the other” allowing different forms of hierarchy. Genetic classification profoundly describes the essence and character of a human being to the cellular level. Genetic classification demonstrates power and danger because, “it involves biological categories that may be confused and conflated with race. Any resulting reification of social categories of race as biological constructs risks new forms of exclusion and stigma.”³⁰⁰

The OMB, PTO and biobanks created an infrastructure of racialization which incorporated racialized labels for groups whose DNA samples they stored, which resulted in the assertion of racial difference and genomics becoming the proxy for reading race.³⁰¹ Regardless of the international science community's statements that race is a myth, the biomedicalization of race became a priority. Researchers in science and medicine argued that race and equity is a valid reason to use race as a means for research. For example, Dr. Francis Collin said, “We need to try to understand what there is about genetic

²⁹⁹ Bell, *Reimagining (Bio)Medicalization*, 179.

³⁰⁰ Kahn, *Race in a Bottle*, 33.

³⁰¹ Bell, *Reimagining (Bio)Medicalization*, 59.

variation that is associated with disease risk, and how that correlates, in some very imperfect way, with self-identified race, and how we can use that correlation to reduce the risk of people getting sick.”³⁰² Collins statement was the same rationale used in BiDil’s 1,050 “self-identified African-Americans” A-HeFT study.

The issue with “self-identification” of race is that it is based on subjectivity. Self-identification has no contextual validity, poor proxy of other people’s perception, excludes people who cannot self-identify (i.e. multi-racial or bi-racial individuals), no use related to research questions on ancestry, and does not reflect the descent and ethnic origin of individuals.³⁰³ Self-identification can be empowering and have elements of freedom but it is a structural process predetermined by a set of classification recognized and enforced by government (i.e. OMB and PTO).

In the American context, the precedent of racial self-identification was never set by individuals but by the government over such individuals. However, American influences of self-identification, described in the book *Racisms: from the Crusades to the twentieth century*, came from Carl von Linnaeus and Johann Fredrich Blumenbach. Swedish botanist Carl von Linnaeus (1707-1778), known as the Father of Taxonomy, created the classification of skin color and first modern study of man. German anthropologist Johann Fredrich Blumenbach (1752-1840) included skin color, skull, and the physiognomy of man in 5 categories and coined the term Caucasian from the

³⁰² Bell, *Reimagining (Bio)Medicalization*, 180.

³⁰³ Whitmarsh, et al., *What's the Use of Race?*, 128.

Caucasus Mountains.³⁰⁴ Linnaeus and Blumenbach are important figures in the classification of racial groups.

Race, ethics, and self-determinism are influenced by social, political, and historical discourse controlled by the government. Eugenic history tells us that no one knows who they are until they are told by society and the society they are in is dictated by its government. A pertinent example is former Spokane, Washington, NAACP chapter president Rachel Dolezal. Dolezal created national headlines posing as an African American woman who was born a white woman.³⁰⁵ She attributed to herself a black identity but by an ingrained racial classification could not self-identify by societal terms. Self-identification does not have legitimate consensus among scientists and geneticists because it is not consistent with findings on the genetic level. For example, an interview with 30 geneticists used OMB categories of race in their studies and admitted the vagueness in classification and scientific inadequacy.³⁰⁶

Genetic variation is very complex within a group. Self-identification is used as a component in studying populations. Epidemiological research should be read through genetic ancestry and genome geography. Genetic ancestry alludes to the differentiations of populace. Geneticists use specific technologies to measure differences through genome-wide association studies (GWAS). GWAS researchers do not use race in their studies but dispute their GWAS for disease associations require methods for accounting for population differences. The GWAS researchers developed tools that are more

³⁰⁴ Bethencourt, Francisco. *Racisms: from the Crusades to the twentieth century*. Princeton University Press, 2014, 250-253.

³⁰⁵ Johnson, Kirk., et. al. "Rachel Dolezal, in Center of Storm, Is Defiant: 'I Identify as Black.'" *New York Times*, June 16, 2015. Accessed on July 7, 2015.
<http://www.nytimes.com/2015/06/17/us/rachel-dolezal-nbc-today-show.html>

³⁰⁶ Wailoo, et al., *Genetics and the Unsettled Past*, 52.

accurate than race groups accounting for population differences.³⁰⁷ Genome geography is the tools and practices of human genetics, “bits of genomic sequence become associated with specific geographic locations, posited as the place of origin of people who possess these bits.”³⁰⁸

Specifically, the tool used is EIGENSTRAT, a population genetics software technology. EIGENSTRAT is the type of technology that “moves from genetic similarity to genetic ancestry to genome geography.”³⁰⁹ GWAS focus on genetic markers called single nucleotide polymorphisms (SNPs). SNPs are markers of individuality and descent through parents. A SNP is a single base pair position in genomic DNA “which two or more possible sequence alternatives (called ‘variants’) can occur. Researchers genotype each DNA sample, at each marker, to determine the pattern of variants in each case and control individual. Geneticists estimate that there are about 10 million SNPs across the approximately 3 billion bases of the human genome, some of which lie within the approximately 20,000 to 25,000 genes.”³¹⁰ This means that there is a small genetic difference within humanity.

GWAS researchers use SNPs findings to determine which SNPs are related to disease. In human genetic variation studies, SNP variants can vary across humans a SNP variant that is ordinary (or high in frequency) in one populace may be uncommon (or at low frequency) in another. It is possible the geneticist’s SNPs findings were collected and labeled using racial or ethnic descriptors by group, but they declined to use such information. It is the ancestry and geographic location that should inform research for

³⁰⁷ Fujimura, “Different differences,” 6.

³⁰⁸ *Ibid.*, 7.

³⁰⁹ *Ibid.*

³¹⁰ *Ibid.*, 9.

disease markers not race. It is important to understand geography and ancestry have a profound influence on physical attributes and disease of populations. A great example is the Pima Indians who, “have unusual susceptibility to non-insulin- dependent diabetes mellitus, and the people of Gambia, in whom polymorphisms in the *NRAMP1* gene influence susceptibility to tuberculosis and the germ line *BRCA1* mutations that render Ashkenazi women susceptible to breast cancer resulting in generational inbreeding.”³¹¹

One has to put into account an estimated 400,000 years of geographic scattering, genetic mixing and societal disorder among ancestors. Physicians, in the Intramural Research Program of the National Human Genome Research Institute and the National Institutes of Health study, were skeptical about BiDiI related to the issues of genetic mixing. There is not genetic proof that African Americans are genetically different than other racial groups. Consequently, Africans and African Americans are more genetically diverse among each other. The continent of Africa shows,

DNA analysis of present day Africans reveals fourteen ancestral population clusters. DNA among African populations tends to be more variable and distinct than among populations from other continents. Even the term African American makes no sense genetically, as it implies unified population. The 20 percent average admixture of European alleles in African Americans, as well as the great genetic variation among different African populations, belies this biogeographic generalization.³¹²

An allele is several forms of gene mutations that produce hereditary variation. It is evident certain alleles differ among certain populations.

Alleles are, “variant genes originated as mutations that proved advantageous under particular environmental conditions. In central and western Africa, for example, several independent mutations in the b-globin gene gave rise to different sickle

³¹¹ Schwartz, Robert S.” Racial profiling in medical research.” *The New England Journal of Medicine*. 344. 18 (May 3, 2001): 1392-1393.

³¹² Wailoo, et al., *Genetics and the Unsettled Past*, 59.

hemoglobins, each with a distinct geographic distribution and phenotype.”³¹³ These mutations multiplied throughout the populace as a form of defense against malaria. The mutation went to Iran, Greece, Turkey, Saudi Arabia, and other areas by migration and slavery. Another example is the FyO allele that is exclusively carried by West Africans and no other African or world population.³¹⁴ Human genomes are 3 billion base pairs spread across 23 chromosomes are 99.9% similar to one another with 0.1% difference (3million pairs) with a smaller selection of 0.1% provide the raw material for locating the source of difference.³¹⁵ Diseases like sickle cell anemia and cystic fibrosis have nothing to do with race but a reality of geography, ancestry and recessive mutations in specific genes. Hence, racialized medicine implies asymmetry in genetics.

Since ancestry and genome geography are better resources in discovering the origin and causes of disease, the reason researchers use uncritical notions of race in research should be challenged. The issue is researchers’ bias using race in research, trials, and studies. GWAS and EIGENSTRAT technologies present medical geneticists with an exact opportunity for data and research results. Rather than using the subjectivity of race or ethnic categories in the process of their research. This is possible by finding fresh ways, through GWAS and EIGENSTRAT technologies, of doing genetic research on complex diseases. In the process of receiving samples of race or ethnic categories they, “need not be analyzed in those categorical terms.”³¹⁶ EIGENSTRAT does not require the use of racial labels to describe research samples. Whoever decides to label and publish their analyses in terms of a racial category are doing so by their own discretion. As I

³¹³ Schwartz, “Racial profiling,” 1393.

³¹⁴ Wailoo, et al., *Genetics and the Unsettled Past*, 53.

³¹⁵ Ibid., 16.

³¹⁶ Fujimura, “Different differences,” 21.

mentioned earlier, the National Institutes of Health (NIH) Revitalization Act encourages the inclusion of women and racial minorities in clinical research. It also,

mandates that practitioners in clinical and basic biomedical research receiving federal funding should *report* on the diversity of their research subjects according to racial and ethnic categories designated by the OMB. The regulations do *not require* either that the researchers must include members of all groups in their studies or that the researchers must *analyze* their samples using race categories (*Emphasis added*).³¹⁷

GWAS technologies allows researchers to study complex diseases without the concept of race. It is the ethical duty of researchers to be self-aware of research bias and show an unprecedented approach to discontinue racial fatigue in biomedical research.

Race-based medicine is a step in the wrong direction because genetic relatedness overwhelmingly outweighs differences in human variation. Race is dependent on one's cultural context which makes race and genetics ambiguous and ripe for misappropriation and misinterpretation. For example, NitroMed used the term African American patient and the FDA used the term black patient.³¹⁸ Race as a proxy for disease not only creates uncertainty but it can result in generalizations and stereotypes which can harm black patients.

BiDil is harmful because it does not work in every African American or Black heart failure patient as the term "black heart drug" implies. Since African Americans or black individuals are genetically diverse, there cannot be a "one size fits all" drug.

Adverse Drug Reactions (ADRs) to BiDil will inevitably be a dangerous reality because of the wide variability in its efficacy and toxicity. ADRs account for 100,000 patient deaths, 2.2 million injuries per year, and cost \$174.4 billion dollars in the United States

³¹⁷ Fujimura, "Different differences," 21.

³¹⁸ Kahn, *Race in a Bottle*, 10.

with a \$101 billion dollar expense that could have been avoided.³¹⁹ BiDil's fast and cheap process ensures risk of ADRs for a population that is unethically simplified. The FDA's approval using race as a proxy for disease superseded scientific fact, which aggressively aided BiDil's race-based trend of clinical minstrelsy.

BiDil's race-based relatives were AstraZeneca's Iressa (gefitinib) and Alcon Laboratories' TRAVATAN. Iressa is a drug for non-small cell lung cancer (NSCLC), which causes 80% or 800,000 lung cancer deaths per year in Asia.³²⁰ The "self-identified" East Asian participants were claimed to have an efficacious reaction to the drug approved by The Advisory Committee of the Japanese Ministry of Health.

AstraZeneca's CEO Tom McKillop stated,

As a responsible company, we have voluntarily withdrawn promotion of the product in the US market while we work with the FDA to ensure that Iressa is only taken by patients who are deriving from benefit. The dilemma we all face is that many people clearly benefit from Iressa, but it is currently difficult to determine exactly which are the patients most likely to do so. The advantages in patients of *Asian origin* demonstrated in our clinical trials and their experience to date has led the Advisory Committee of the Japanese Ministry of Health to recommend the continued availability of Iressa and has led to approval for the marketing of Iressa in China and other Asian markets (*Emphasis added*).³²¹

Similar to NitroMed, AstraZeneca's findings did not have another racial control group to determine adequate racial efficacy of Iressa. McKillop's uncertainty illustrates an uncanny resemblance to the FDA's reaction to BiDil asserting race-based components without the proper clinical process to determine the proposed drug's efficacy. Another racialization of a condition was glaucoma.

TRAVATAN are eye drops that aid in the issue of glaucoma, which African Americans are at greater risk. African Americans are six to eight times at risk to develop

³¹⁹ Wailoo, et al., *Genetics and the Unsettled Past*, 166-167.

³²⁰ *Ibid.*, 176.

³²¹ *Ibid.*

glaucoma compared to the general population.³²² Glaucoma is an issue to the African American community but glaucoma is not only a “black issue.” Glaucoma is an issue for the public health for the general population. The race-based classification of conditions or diseases creates inaccurate scientific perceptions of different types of groups. Race-based health differences are “biologic expressions of race relations,”³²³ which are interpreted as real demographic issues that need to be resolved. The FDA justified their fourth reason for approving BiDil through the lens of equity and justice.

Health Inequity and Discrimination

The FDA’s fourth justification for approving BiDil was to reduce social and demographic injustice and inequity. The FDA asserted, “Race and other demographic characteristics have long been important to consider in analysis of trials and as a matter of equity and justice.”³²⁴ Effectiveness in therapeutics requires one to look at the entire social context of a group. Misunderstanding and ignorance of a group does not aid in proper alleviation of disease. Simply giving a group a pill does not instantly remove illnesses and diseases. Legitimate pharmacology and therapeutics engages with the group within their historical and social context, to better understand the source of the illness. A Pharmaceutical company expediting drugs as a quick fix is a lethargic solution and intensifies inequity instead of diminishing it. Race-based medicine continues health inequities by not focusing on discrimination, psychosocial stress and diet and nutrition as factors.

³²² Rose, Nikolas S. *Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton: Princeton University Press, 2007, 181.

³²³ Kahn, *Race in a Bottle*, 6.

³²⁴ Temple, “BiDil for Heart Failure in Black Patients,” 58-59.

Minorities suffer from health inequities in the United States. In American medicine, “epidemiological data has reflected and reinforced scientific thinking about race for more than 200 years.”³²⁵ Epidemiological data shows an overwhelming amount of evidence of racial inequalities in morbidity and mortality, which African Americans rank the highest. For example, the age-adjusted death rate for African Americans was 30% higher than whites. Specifically, rates from hypertension, kidney disease, diabetes, hypertensive renal disease, and septicemia are twice as high in African Americans as in white Americans. In response to heart related issues, “Cardiovascular disease accounts for the largest share of black-white difference in mortality (34.0%), but there are substantial contributions from infections (21.1%), trauma (10.7%), diabetes (8.5%), renal disease (4.0%), and cancer (3.4%).”³²⁶ These horrible statistics are a result of historical disregard of African Americans by the American medical system. For example, the discrimination behind the Tuskegee and Henrietta Lacks studies are disturbing historical events that African Americans have been victims of a medical system encapsulating them into discriminatory labels by the marker of race.

Discrimination is the treatment, consideration, and distinction of where a person or group belongs rather than on individual merit. Racism is the belief that all members of each race possess characteristics or abilities specific to that race, especially so as to distinguish it as inferior or superior to another race or races. Labels enforced on African American patients can produce negative assumptions and pre-conceived notions by the doctor. The consequence of labels puts a huge mental strain on black patients. This is an

³²⁵ Gravlee, Clarence C. “How race becomes biology: Embodiment of social inequality.” *American Journal of Physical Anthropology*. Volume 139, Number 1 (May 2009), 48.

³²⁶ Ibid.

important factor in mental health in the black community. Negative factors that contribute to poor mental health outcomes include, “unfair treatment and social disadvantage as well as other social stressors, such as inadequate levels of social support, neuroticism, the occurrence of life events, and chronic role strain.”³²⁷ Labels create poor communication, which worsens health disparities. A patient having a transparent relationship with their physician is more likely to have better health outcomes. In contrast, a patient feeling judged is more reluctant to discuss their health because they feel condemned by a false label attributed to them, which worsens health outcomes.

Race-based medicine does not reduce the consequences created by discrimination and racism. Discrimination imposes an unbearable amount of stress on African Americans. The history of racism in America has left African Americans in poor health for generations. Racism influences every facet of American society. For African Americans, racism contributes to health disparities. The psychosocial stress factor is significant in black health. Stress effects every element of one’s being. The unchangeable marker of race becomes a constant stressor every day, “it reveals intricate relationships among the brain, immune system, autonomic nervous system, and the hypothalamic pituitary- adrenal (HPA) axis, as well as, the ways in which unhealthy environmental stimuli can “get under the skin” of individuals to cause negative health outcomes.”³²⁸ An individual experiencing a lifetime of racism (from birth to adulthood) has a higher risk of diabetes, stroke, and hypertension.

³²⁷ Mays, Vickie M., et al. “Race, Race-Based Discrimination, and Health Outcomes Among African Americans.” *Annual Review of Psychology*. January 2007 Vol. 58, 206.

³²⁸ Ibid., 205.

Anthropologist Chris Kuzawa explains discrimination and stress creates a vicious cycle generationally. Kuzawa declares, “The immediate consequence of this intergenerational effect is a higher risk of adverse birth outcomes but there is also a lingering effect into adulthood, as adult chronic diseases like heart disease and diabetes can be traced in part to prenatal and early life conditions. Thus, the cycle begins again.”³²⁹ A good example of this is comparing infants’ birth weight for U.S.-born black women, African-born black women, and U.S.-born white women.

In regard to birth weight, African-born black women’s babies were almost identical to U.S.-born white women’s babies. However, the birth weight results negatively went down for U.S.-born black women. Interestingly, the benefit of African and Caribbean-born women decreased, in a single generation. The results show, “The first generation of girls born in the United States to mothers of African descent grew up to have girls of their own with lower mean birth weights a trend that shifted the distribution toward that of U.S.-born black women.”³³⁰ This suggests discrimination has a significant impact on black birth rates. Socioeconomics, space, and place affect black birth rates and other health and wellness factors. A drug based on race is not a health solution but a distraction that ignores the greater issue of environmental racial discrimination that contributes to health inequity in communities of color.

Race-based medicine leaves the patient in a helpless state. The patient’s disease is not due to one’s personal responsibility but as a result of a racial classification out of one’s control. Clinical focus should not be on race-based medicine, but on preventative

³²⁹ Gravlee, “How race becomes biology,” 52.

³³⁰ Ibid., 53.

means toward health disparities. There are many solutions that can alleviate health inequity and discrimination in minority communities. Two essential responses to health inequity are strengthening the physician-patient relationship through the physician's cultural competency, empathy and awareness with a keen focus on diet and nutrition.

Physician-Patient Relationship: Cultural Competency

Race-based medicine “normalizes” patient care. It assumes homogenous models of care within racial groups, which is inconsistent with the individuality of every patient regardless of race. The role of the physician is to recognize and correct their lack of awareness and provide clear communication between themselves and their patients. Physicians should not categorize patients by race. Categorization based on race and socioeconomics can bring expectations based on unproven stereotypes, labels, and assumptions. The best option for physicians is to personalize patients. A physician's patient identification should not be the “5’10 black male weighs 200 pounds.” Better identifiers would be “Jim, the engineer with a wife and three kids.” Categorization detaches a physician but personalization engages the physician with the patient's life.

Race-based medicine affects the physician's cultural competency because research based on false assumptions about racial groups portrays minorities in an inaccurate way, which influences the physician's perception and way of practice. Historic experiences impact African Americans trust in medicine. The devaluating of black bodies is the foundation of western medical history. One key action doctors can take in improving relations with minority communities is recognizing minority patient's

collective histories and make it an individual sacred act to value minority patients by expressing that value in the clinical practice and public health.

Physicians need to have a solid sense of cultural and self-awareness, because it impacts on decision quality. Quantitative errors results for only a small fraction of misdiagnoses and mistreatments. Most misdiagnoses and mistreatments are qualitative errors in thinking.³³¹ Interacting with the patient from an individual and personalized level helps to alleviate bias and stereotypes.

Race-based medicine gives physicians a lethargic means for diagnosing a patient based on external traits compared to assessing the patient's unique social status. A physician's most dangerous practice is allowing clinical statistics to supersede personal communication in patient care. When physicians focus on numbers to influence thinking, judgmental and normative errors will take place. As a result, "a conscientious professional develops and follows an incorrect strategy. A physician committing this kind of error violates a norm of conduct, particularly by failing to discharge moral obligations conscientiously."³³² The development and progression of incorrect strategies and questionable norms of conduct can be a consequence of subconscious and unrealized biases or phobias by the physician and race-based research.

Self-awareness cannot be limited to personal cognition, but emphasis should be among the collective or group awareness among physicians and their support staffs. Physicians need to be aware and acknowledge the predispositions and socioeconomic

³³¹ White III, Augustus A. *Seeing Patients: Unconscious Bias in Health Care*. Harvard University Press (2011), 204.

³³² Beauchamp, Tom., and James Childress. *Principles of Biomedical Ethics*. (Oxford University Press 6th Ed; 2008), 34.

inequities existing in minority groups. Physicians and their staff should understand the community and the people they are serving.

Personal, cultural, and collective awareness among physicians are essential for effective communication. The physician-patient relationship should revolve around communication which is, “the fundamental instrument by which the physician-patient relationship is crafted and by which therapeutic goals are achieved.”³³³ The physician should not have biases, phobias, and preconceived notions toward patients. Assumptions should be eliminated. Doctors need to ask basic questions, feel comfortable in this process, and be respectful, empathic, and nonjudgmental. Communication is most effective when there is full openness between the doctor and patient.

The patient should not verbally express themselves solely by communicating the physical issue, but should have the opportunity to talk about their life. As a result, the patient is individualized instead of being categorized. Personal conversation between the patient and doctor lays a firm foundation to fight subconscious biases the physician has towards the patient. Communication connects the physician with the patient. The physician communicating and understanding the patient removes labels that are a result of race-based statistics. Such practices results in veracity, and creates and encourages respect. Respect is a fundamental aspect of care, which “discerns the personhood of human beings as creatures able to persevere powerfully and creatively in their aims.”³³⁴ Respect shows the physician has compassion (active regard to another’s welfare), and allows the physician to discern patient’s judgments, decisions, fears, attachments, likes,

³³³ White, *Seeing Patients*, 199-200.

³³⁴ Stith, Richard. *Toward Freedom from Value*. The Jurist 38 (1978), 170.

and hates. The patient's personal sharing creates a foundation of trustworthiness and integrity.

Empathic Communication

The process of reconciliation starts with an empathic relationship. Self-awareness opens up the physician to become empathetic. Empathic understanding is also central to the provision of all person-centered, relationship-based health care. This capacity for accurate and compassionate empathy is partly contingent on the subjective experiences of the observer the extent to, which he or she has experienced the emotions being imputed to the other.³³⁵ In other words, empathy is the ability to understand another's experience, to communicate and confirm that understanding with the other person and to then act in a helpful manner. The physician, for example, who has not grieved cannot fully simulate (empathize with) a grieving patient although during the process of therapy the practitioner will learn more about the range of feelings and behaviors that may characterize this state of mind.

The accuracy of this empathic process with patients is nevertheless often difficult for health professionals to attain. Communities undergoing rapid transition, disadvantaged, or challenged in health care delivery need culturally competent and empathetic physicians. Any lack of shared assumptions or values can result in demoralization and depersonalization of both the health care professional and the patient. Race-based medicine encourages assumptions by attributing a group to a disease. Specifically, African Americans being linked to heart disease, heart failure and high

³³⁵ Cox, John L. "Empathy, Identity and Engagement in Person-Centered Medicine: The Sociocultural Context." *Journal of Evaluation in Clinical Practice*. Apr 2011, Vol. 17 Issue 2, 351.

blood pressure. Such associations can make the patient feel they are apart of a general health problem they have no control over.

Lack of empathy and cultural competency can dehumanize the patient. It makes the patient feel inadequate, insignificant, and objective. Many of the criticisms of medical care voiced by minority patients refer to what they perceive as inadequate interpersonal and communication skills, rather than deficiencies in the technical or procedural aspects of their care. Research implies that explicit articulation of empathy and other altruistic behaviors may benefit both physician and patient.³³⁶ Yet, oddly enough, empathy is articulated infrequently in most physician-patient relationships. Moments when emotions were expressed by the patients were often overlooked by the physicians. For example, approximately 200 such moments, termed empathetic opportunities, the oncologists responded 22% of the time, and with lung cancer patients the empathetic response was 11%.³³⁷

In a November 2015 *New York Times* article titled “Minorities Get Less Pain Treatment in E.R.,” suggests whites receive more pain treatment in emergency rooms compared to African-Americans and other minorities. The article was based out of the Center of Disease Control (CDC) four year study. The sample size was 6,710 visits to 350 emergency rooms by patients eighteen and older with acute abdominal pain. Compared with non-Hispanic white people, non-Hispanic blacks and other minorities

³³⁶ Buckman, Robert., et al. “Empathic responses in clinical practice: Intuition or tuition?.” *CMAJ: Canadian Medical Association Journal*. 3/22/2011, Vol. 183 Issue 5, 569.

³³⁷ Ibid.

were 22% to 30% less likely to receive pain medication.³³⁸ This study can implore the idea of black hardness as a reason why African Americans are treated differently. Such beliefs are still prevalent in society but I would not suggest this idea to be a legitimate proxy for physicians and their treatment of patients.

The issue had to deal with communication. As Dr. Adil H. Haider, the director of the Center for Surgery and Public Health at Brigham and Women's Hospital in Boston, said: "It may be that different people communicate differently with their providers. If we as providers could improve our ability to better communicate with patients so that we could provide more patient-centered care, we'll be making several steps toward reducing and hopefully eliminating these disparities."³³⁹ Overall, the physician's interactions and understanding the patient's vulnerability was a very important element in patient care.

The explanation of physicians' lack of empathy, interpersonal skills, cultural competency and communication skills further confirms they have not received sufficient training to develop or enhance the necessary interpersonal and culturally competent skills for patient-centered care. Physicians who were trained dramatically improved on communicating with their patients. Controlled, randomized studies, conducted by Dr. Balint at the Tavistock Clinic, have confirmed and extended that physicians attending an 8 hour communication skills training course showed statistically significant improvements in empathic behaviors such as asking for patient's understanding and expectations, offering reassurance, setting an agenda for the medical visit, and eliciting

³³⁸ Bakalar, Nicholas. "Minorities Get Less Pain Treatment in E.R." *New York Times*. November 30, 2015. Accessed on December 2, 2015. http://well.blogs.nytimes.com/2015/11/30/minorities-get-less-pain-treatment-in-e-r/?ref=health&_r=0

³³⁹ Ibid.

the full spectrum of patients' concerns.³⁴⁰ Physicians who had received training were able to recognize patients' "psychosocial problems 50% of the time, compared with 37% for the control group of physicians who had not participated in the 8 hour course."³⁴¹

Physician's Self Awareness

Race-based medicine obstructs physicians' training rather than improving it. Labeling and assumptions through race-based research can create lack of self-awareness, which produce malpractice situations. Malpractice is the negligence, misconduct, lack of ordinary skill, or breach of duty in the performance of a professional service that results in injury or loss.³⁴² Less studied, but now receiving greater attention, are measures of how the liability system affects clinical care. The pressing need to improve quality and efficiency in health care mandates any liability reform also be evaluated on the basis of clinically relevant metrics. Evidence suggests one way to achieve quality is by providers showing more empathy to patients. Investigators at Jefferson Medical College in Philadelphia studied how medical outcomes of diabetics treated on an outpatient basis were affected by empathy, defined as "a predominately cognitive attribute that involves an understanding and an intention to help."³⁴³ The investigators found that physicians with high empathy scores had patients with higher rates of favorable clinical outcomes than those with lower empathy scores. In contrast, race-based medicine already asserts an unfavorable prognosis and empathy toward the patient and determined the proper therapeutic approach is through pharmaceutical drugs.

³⁴⁰ Neuwirth, Zeev E. "Physician empathy—should we care?" *The Lancet*. 350.9078 (Aug 30, 1997), 606.

³⁴¹ Neuwirth, "Physician empathy," 606.

³⁴² "Malpractice." *Encyclopedia Britannica*. Encyclopedia Britannica Inc., 2014. Web. 10 Nov. 2014. <<http://www.britannica.com.ezproxy.drew.edu/EBchecked/topic/360514/malpractice>>

³⁴³ McKnight, Whitney. *Infectious Disease News*. 24. 6 (June 2011)

In contrast to race-based medicine, clinical empathy and cultural competency are essential elements of quality care, and is associated with improved patient satisfaction and adherence to treatment as well as fewer malpractice complaints. Empathetic engagement in patient care can contribute to patient satisfaction, trust and compliance, researchers concluded in a recent issue of *Academic Medicine*.³⁴⁴ The lead investigator on the empathy study and author of the textbook *Empathy in Patient Care* Mohammadreza Hojat, PhD asserted, “Malpractice claims against physicians are more likely when the physician fails to establish a trusting relationship with the patient,” says. Hojat’s findings underscore those of a 1997 study published in *The Journal of the American Medical Association*, which stated that, “Primary care physicians who used more statements of orientation (educating patients about what to expect and the flow of a visit), laughed and used humor more, and tended to use more facilitation (soliciting patient’ opinions, checking understanding, and encouraging patients to talk) experienced less medical claims than those who were less engaged.”³⁴⁵

Race-based medicine does not allow patient to have opinions of prognosis because patient diagnosis is already pre-determined through race-based research. Patients do not have the option to express their opinion of the diagnosis. The patient’s understanding of the disease is misinterpreted by the assumptions of race. For example, an African American heart failure patient associates disease to their race rather than personal responsibility of well-being (e.g. diet, exercise, and managing stress). Associating a personal ailment to one’s race is dehumanizing. As a result, blacks and Hispanics are more comfortable with physicians of their own race to avoid stereotypes.

³⁴⁴ McKnight, “Infectious Disease News,” 24. 6.

³⁴⁵ Ibid.

Stereotypes and categorizations enhance the perceptions of similarities within groups and differences between groups. Physicians interpret others by their own perceptions of stereotypes which influence expectations, inferences, and impressions. Theory and research on clinical decision making suggests ambiguities in the physician's understanding may result in health disparities which are results of a physician's belief that blacks are less likely to comply with treatment.³⁴⁶ Such disturbing responses rejuvenate similar ideas of the non-complaint black slave, soldier and prisoner. Stereotypes are the consequences of the racist ideologies and oral traditions of American medicine and biology. It is a medical ritual handed down by the mechanism of a medical tradition that damages clinical care.

Black patients have less time in the clinical practice with white doctors who are viewed as more assertive verbally. African American patients were four times more likely to believe they will experience racism in doctor's offices with 58% of hispanics and 65% of blacks very or somewhat concerned with racism in medical practice with family members.³⁴⁷ Also, 64% of blacks believe they receive lower quality of care, one-third of blacks experience racism in some part of their lifetime when seeking healthcare, and 95% of black report discrimination.³⁴⁸

The physician's cultural competency, empathy, and awareness are crucial elements in improving health inequity in the clinical practice. When minority patients trust their physicians and doctors correct unconscious bias, minority communities can

³⁴⁶ Smedley, Brian D., Adrienne Y. Stith, and Alan R. Nelson. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, D.C.: National Academy Press, 2003, 167, 173.

³⁴⁷ Ibid., 136.

³⁴⁸ Ibid.

improve their health outcomes. Another key element in alleviating health inequity and discrimination is health education and access to healthy foods. Poor access to healthy food is an important factor in health disparities.

Diet and Nutrition

Scotland, in the early 1990s, a resident of a public housing sector scheme used the term food desert for the first time. Since that time, researchers has used food desert for different meanings in research. Food deserts were defined as “urban areas with 10 or fewer stores and no stores with more than 20 employees.”³⁴⁹ Food deserts can be urban areas where individuals cannot buy food due to income. Also, food deserts possess unhealthy type and quality of foods rather than the number of foods, type and size of food stores available to residents (i.e. farmers’ markets/supermarkets vs. fast food chains). These definitions make it difficult to come up with a general agreement of what is an adequate definition of a food desert and what guidelines are required for identifying food deserts.

In the United States, food deserts are a health phenomenon. Many theories have been proposed on how food deserts came into existence. The first theory explains the expansion and closure of supermarkets, which hindered supermarket growth in urban/inner city areas, and stimulated the growth of large chain supermarkets in affluent suburban areas where consumers have better quality, variety and price for food options. In the suburbs, stores are more suitable for consumers having longer business hours and better parking options. These supermarkets have crippled the smaller, “mom and pop,”

³⁴⁹ Walker, Renee E., Christopher R. Keane, and Jessica G. Burke. “Disparities and access to healthy food in the United States: A review of food deserts literature.” *Health & Place*. 16, no. 5 (September 2010), 876.

neighborhood grocery stores competitive edge. Consequently, the neighborhood grocery stores are going out of business and individuals who want quality food will have to access it by a car or public transportation, which limits the geographical access to quality food. By this theory, an independent retailer asserts a food desert is “an area where high competition from the multiples [large chain supermarkets] has created a void.”³⁵⁰

The second theory reflects on the demographics of urban areas between 1970 and 1988. Within this time period, geographic and economic segregation grew when households of higher socioeconomic status moved from the inner-city to the suburbs. This reallocation cut the median income of urban areas and “forced nearly one-half of the supermarkets in the three largest U.S. cities (i.e. New York, Chicago, and Los Angeles in the 1970s and 1980s) to close.”³⁵¹ As urban areas become more densely populated, supermarkets find urban areas unappealing due to the scarcity of real estate and zoning laws. It is very difficult for large supermarkets to find an adequate size of land, because properties are sold in smaller pieces, and since most individuals in urban areas are at a lower socioeconomic status the monetary gain will not be in large chain supermarkets best interests.

Indeed, residents living in urban areas have their challenges obtaining healthy food. Research shows individuals living in rural communities encounter spatial disparity, because greater distances enhance one’s inability to obtain essential goods and services. However, research on spatial distribution of food resources in rural communities is very scarce. There is a huge need for more research to be done regarding rural communities

³⁵⁰ Walker, et al., “Disparities and access to healthy food,” 876.

³⁵¹ Ibid., 877 (*Emphasis Added*).

and its relation to food deserts. Nevertheless, let's focus on New York City and its relation to supermarket access in specific communities.

The Journal of Economic Geography did a study “to illustrate the effects on the measurement of disparities in food environments of adjusting for cross-neighborhood variation in vehicle ownership rates, public transit access, and impediments to pedestrian travel, such as crime and poor traffic safety.”³⁵² The study used geographic information systems data of 2,172 tracts from the 2000 census for New York City supermarkets, fruit and vegetable markets, and farmers' markets. The analysis used racial/ethnic and economic composition as categories. Specifically, the racial/ethnic and economic composition was broken down into five categories: majority (more than half) non-Hispanic white, majority non-Hispanic black, majority Hispanic, majority Asian or Pacific Islander, and a remaining group of census tracts which did not have any racial or ethnic group as a majority.

Additionally, the study compared 50% of foreign-born residents to those with 50% or less foreign-born population. The economic measurements were recorded by quartiles based on poverty rates, defined as the proportion of residents living below the federal poverty line.³⁵³ The study used supermarkets data, from 2005, which categorized all grocery stores as supermarkets that were not termed as “convenience stores,” had 17 or more employees, and had annual sales of \$2 million. The studies result illustrated “New York City contains many densely settled neighborhoods that are characterized by mixed land use; in such neighborhoods, which are particularly prevalent in Manhattan

³⁵² Bader, Michael D. M., et al. “Disparities in Neighborhood Food Environments: Implications of Measurement Strategies.” *Economic Geography*. 86, no. 4 (October 2010), 409.

³⁵³ *Ibid.*, 414.

and the innermost sections of Brooklyn, Queens, and the Bronx, the density of healthy food outlets is relatively high.”³⁵⁴

Based on these results, the areas with the lowest access to healthy foods are in the outer edges of Bronx, Queens, Brooklyn, and in Staten Island. Since the average distance calculated was 800 meters, one needs to note that the distance of travel may not be adequate to confirm travel as a burden. The effects of smaller retailers, fruit and vegetable markets in relation to disparities by neighborhood race/ethnic, immigrant, or poverty had inconclusive measures regarding healthy food access.

Another interesting study by the *American Journal of Preventive Medicine* examined how urban food environments change over the course of one year. The study was based in Buffalo, NY. The data was from the 2000 U.S. Census, a 2010 listing of city supermarkets, 2011 government records and mapped location of urban farmers’ markets.³⁵⁵ The distances from block groups to supermarkets and farmers’ markets were calculated. A 2011 written computer simulation examined the market closest to each block group for 52 weeks. The results show the average distance to supermarkets from block groups with poverty levels “in the top 10th percentile is greater than that across all block groups during winter and spring months.”³⁵⁶

This study reflects that the wealthier block groups have greater access to supermarkets and farmers’ markets compared to the poorer block groups, because “wealthier households have more economic resources and therefore attract farmers who

³⁵⁴ Bader, et al., “Disparities in Neighborhood Food Environments,” 417.

³⁵⁵ Widener, Michael J., Sara S. Metcalf, and Yaneer Bar-Yam. “Dynamic Urban Food Environments: A Temporal Analysis of Access to Healthy Foods.” *American Journal of Preventive Medicine*. 41, no. 4 (October 2011), 439.

³⁵⁶ Ibid., 440.

perceive these regions as being areas with more demand.”³⁵⁷ During farmers’ market season, low income neighborhoods have greater access to healthy food in warmer weather compared to colder weather, and low income areas with a higher frequency of poverty have a higher average distance to supermarkets and farmers’ markets, than all block groups combined during the winter weeks. This can have huge influence on how food outreach programs are carried out. Poorer neighborhoods could be used as leverage in warmer weeks and wealthier households in the winter.

The NYC and Buffalo, NY studies show that access to healthy food is a complicated task depending on where you are from. Some areas may be less susceptible than others. The NYC study is an exception to geographic access to healthy food to low income households. According to the US Department of Agriculture (USDA) Economic Research Service (ERS) and the 2010 Census and supermarket data, “limited access to major food outlets such as grocery stores and supermarkets affects over 23.5 million people living in 6,529 different Census tracts. 29.7 million people who lived in low income areas were over 1 mile from a supermarket.”³⁵⁸ The NYC analysis differed on access being an issue with healthy food, but it did assert, “The relationship between physical distance and travel burden is likely to depend on both individual/household and neighborhood characteristics.”³⁵⁹ Arguably, lower income households and neighborhoods can vary in physical access to food, but financial and geographical access creates huge challenges. Furthermore, the geographical and financial challenges low income

³⁵⁷ Widener, et al., “Dynamic Urban Food Environments,” 439.

³⁵⁸ Sohi, Inderbir, Bethany A. Bell, Jihong Liu, Sarah E. Battersby, and Angela D. Liese. “Differences in Food Environment Perceptions and Spatial Attributes of Food Shopping Between Residents of Low and High Food Access Areas.” *Journal of Nutrition Education and Behavior* (2014), 1.

³⁵⁹ Bader, et al., “Disparities in Neighborhood Food Environments,” 412.

households experience to obtain healthy food access is detrimental to these individuals health. These individuals lack of access to healthy foods results in poor nutrition.

Poor supermarket access creates negative outcomes of residents consuming and being exposed to energy-dense food or “empty calorie” food available at convenience stores and fast-food restaurants. Research shows, “a diet filled with processed foods, frequently containing high contents of fat, sugar and sodium, often leading to poorer health outcomes compared to a diet high in complex carbohydrates and fiber.”³⁶⁰ The lack of supermarket access and poor nutrition are results of poverty. As the cost of healthy food continues to rise, barriers to healthy eating are created. People tend to make food choices based on what is available in their immediate neighborhood. This can produces problems since many low-income urban areas have a higher density of fast-food restaurants and corner stores that offer prepared foods compared to higher income areas.³⁶¹ For individuals in low income areas, it is more conducive to consume food that is cheap and local, rather than food that cost more at a farther distance.

Fruits and vegetables are vital for a healthy diet. The 2005 American Dietary Guidelines instructs 4.5 cups (9 servings) of fruits and vegetables daily, based on a 2,000-calorie diet. Americans roughly consume 2.6 cups of fruits and vegetables.³⁶² Most Americans do not meet the 4.5 cup minimum, making the increase of fruit and vegetables intake an important goal for healthy eating interventions. Food environments influence a range of dietary health indicators including obesity rates, as well as the consumption of fruits, vegetables and low-fat dairy products. Failing to consume fruits and vegetables

³⁶⁰ Walker, et al., “Disparities and access to healthy food in the United States,” 877.

³⁶¹ Ibid.

³⁶² Dean, Wesley R., and Joseph R. Sharkey. “Rural and Urban Differences in the Associations between Characteristics of the Community Food Environment and Fruit and Vegetable Intake.” *Journal of Nutrition Education & Behavior*. 43, no. 6 (November 2011), 426.

and other healthy foods daily can lead to a series of adverse health disparities, including obesity, diabetes, cancer, and cardiovascular diseases,³⁶³ within low-income groups.

The Centers of Disease Control and Prevention (CDC) define health disparities as “preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.”³⁶⁴

The rise in obesity rates in the US has been a driving force of research into “obesogenic environments” (food environment–diet relationship). Studies assert food environments that have a lot of fast-food restaurants and few grocery stores were associated with higher odds of obesity among area residents.³⁶⁵ Since food deserts create unhealthy communities, solutions need to be in place to sustain health equity and eradicate food deserts.

The first solution is creating initiatives to educate communities about health. Health literacy should start in low income communities. According to Judith C. Rodriguez, President of American Diabetes Association, “Only 12% of adults have proficient health literacy, as defined by the National Assessment of Adult Literacy (NAAL). In other words, nearly 9 in 10 adults may lack the skills needed to manage their own health and prevent disease. According to the NAAL, 14% of adults (30 million people) have below basic health literacy. These adults are more likely to report their health as poor (42%) and are more likely to lack health insurance (28%) than adults with

³⁶³ Chen, Xiang, and Xining Yang. “Does food environment influence food choices? A geographical analysis through ‘tweets’.” *Applied Geography*. 51 (2014), 82.

³⁶⁴ CDC. Community Health and Program Services (CHAPS): Health Disparities Among Racial/Ethnic Populations. Atlanta: *U.S. Department of Health and Human Services*; 2008.

³⁶⁵ Sohi, et al., “Differences in Food Environment Perceptions,” 1.

proficient health literacy.”³⁶⁶ Policy makers, researchers and health professionals should work together and consider urban environments as entities where health education is a priority. By doing this, health education programs can improve health outcomes and produce cost-effective advancements in diets within low income communities.

More research in the unique dynamics of rural and urban food deserts is needed to better understand how food deserts are created and how they can be prevented. One innovative way to study rural and urban areas is through social media. In a study from *Applied Geography Journal*, food-related activities from social media Twitter, “tweets” provide an ideal method for measuring the exposure to the food environment in real time. The measure reflects food choices people make on twitter and where they decide to eat. The study compares “groups of Twitter users who shop in grocery stores to those who dine at fast food restaurants, we found that the prevalence of grocery stores that stock fresh produce within an individual’s neighborhood may significantly influence him or her to make nutritious food choices.”³⁶⁷ Studies like this can be a great asset in understanding individual behaviors in how they chose food and what reasons are behind their dietary choices.

The second solution is improving food access. In the *American Journal of Preventive Medicine* study, Buffalo, NY had issues with low income households not having consistent access to healthy food through farmers’ markets. Buffalo’s solution was having farmers’ markets accept purchases through the Women, Infants, and Children (WIC) and Seniors Farmers’ Market Nutrition programs. This process can be the blueprint for other communities that are categorized as food deserts. Since location to

³⁶⁶ Rodriguez, Judith C. “Serving the Public: Health Literacy and Food Deserts.” *Journal of the American Dietetic Association*. January 2011, 14.

³⁶⁷ Chen, et al., “Does food environment influence food choices,” 82.

supermarkets is a challenge, it is wise to bring the healthy food to the neighborhoods that need it the most.

Food deserts are making the most financially vulnerable around us ill. Poverty in itself is a disease that negatively impacts the health of individuals. Furthermore, poverty prevents individuals from access to healthy foods through the distance of supermarkets. The lack of access to supermarkets leads to unhealthy eating habits, resulting in health disparities that can be prevented. Through health literacy and better access to healthy foods, food deserts can be eliminated and can aid in the elimination of health disparities.

Race-based medicine hinders a minority groups' self-awareness to make a conscience educated choice by turning their attention toward their physical traits and focusing on their race as a marker for disease. As a result, race-based medicine continues disinformation about race, its relation to disease and the genetic uniqueness of human beings. One should carefully evaluate the social and historical factors that affect the health of minority communities. Race-based medicine undermines the voice, participation, and interdependence of minorities by establishing false assumptions that race is the element for the origin of diseases and capitalizing on recurring eugenic ideologies. Such ideologies affect African Americans' understanding and language of personal health.

As discussed in chapter two, oral tradition has communitive importance in the black community. It is a means where language depends on action or inaction. The fatalistic language of race-based medicine takes away the voice of the minority patient because inevitable illness purports a fixed epidemiological process. Physician's cultural competency, empathy, awareness and better nutrition are good suggestions for better

health outcomes in minority communities. Furthermore, the use of black theology and the black church have given a voice for the minority community in situations when black voices have been quieted. Hence, black theology and the black church are versatile tools that can challenge the push against race-based medicine.

The black church brings justice through health advocacy not allowing the health of oppressed groups to be ignored, challenging the poor socioenvironmental factors that contribute to minority groups' health inequity, and demanding the faulty solution of race-based medicine to be replaced with legitimate social solutions. Black theology is a tool to emphasize autonomy (freedom) in minority communities by encouraging the uniqueness and value of minority communities against the labels race-based medicine enforces. Chapter four will examine race in biblical literature, scripture as a tool for minority patient empowerment, and how faith communities' can play a role in health advocacy.

Chapter 4

A BLACK THEOLOGICAL RESPONSE TO RACE-BASED MEDICINE: RECONCILIATION IN MINORITY COMMUNITIES

So far, we have examined the origins of race-based medicine, the harm race-based medicine inflicts on minority bodies through race-based experimentation, and the false solutions a race-based drug ensues within minority communities. Such areas analyze the minority patient in a physical proxy. Though the mind and body are important entities, we cannot forget about the spirit. Healing is not just a physical practice; it includes spiritual practice. Efficient medicine includes the holistic elements of the mind, body, and spirit. Therefore, the spiritual discipline of black theology can be used as a tool to mend the harms of race-based medicine. It can be an avenue of research to further particular concerns for justice in medical care. Such theology contributes to the discussion of race-based medicine indicating the need for the voice, participation, and interdependence of minorities. Black theology can be used as a tool of healing and empowerment for health equity and awareness by exploring black theology's response to race-based medicine, analyzing race in biblical literature, using biblical literature as a tool for minority patient empowerment, building on past and current black church health advocacy with personal leadership in health advocacy.

Race and Scripture

Black Theology

The African American experience is the testimony of a group that unfortunately went through inhumane, social, political, spiritual, economic, and other systematic

injustices through lived experiences rooted within American race relations. These realities reflect the lived experience of an oppressed and marginalized group. Thus, “black” or “blackness” is not just a symbol of oppression, but of empowerment and endurance through the influence of black theology and its use in the black church.

In response to the fight against discrimination and ongoing dehumanization, the black church was created. African Americans used to share houses of worship with whites. They were not treated as valued children of God. Blacks wanted a place where they can worship freely without being monitored or dehumanized. Worship for African Americans was a means of survival. It was a chance to come together, as a community, and restore strength and hope in a racially cruel society. This is what Dr. James H. Cone describes as a “survival theology” in the black community. For Dr. Cone, “theology cannot be separated from the community which it represents.”³⁶⁸ This truth has been evident ever since the establishment of slavery and it is the duty of African Americans to evaluate the implications of their experience and to be consistent in its commitment to defend its existence.

Black theology “analyzes the oppression of black people, affirms the personhood of black people, and advocates their social and political liberation.”³⁶⁹ It is an extraordinary task to survive in a situation that one’s inevitable and unchanging physical appearance, “one’s blackness,” is the cause of disease in a racially aggressive society. As a result of such racial realities, race-based medicine continues to sustain the labels of race in society and medicine. Black theology gives minorities a voice asserting skin color does not assign one’s inferiority or bondage. Furthermore, it asserts skin color is not a marker

³⁶⁸ Cone, James. *A Black Theology of Liberation*. Philadelphia, Lippincott, 1970, 8.

³⁶⁹ Sanders, “European-American Ethos and Principlism,” 78.

to illness. As Dr. Miguel A. De La Torre suggests, “Liberation is not just a symbol, it should mean a radical break with the status quo designed to maintain oppressive structures.”³⁷⁰ Black theology as survival theology is a response to the labels of race and illness by liberating the minority community to participate and speak out against the stigma of racial disease.

Black theology is a tool that demonstrates multiple black perspectives and experiences. In contrast, race-based medicine encourages a truncated look at black experiences. In order to fully understand the black experience you have to be black. The black experience is fully understood and realized by black persons. This does not mean the black experience is solely homogenous. There are similar themes but the black experience is diverse through its unique cultures, languages, and historical discourse. Rather recognizing the complexity of pathology and epidemiology in a racial group, race-based medicine encapsulates the black illness narrative in general terms. Dr. Cone mentions WEB DuBois comment that the black soul is not learned, “it comes from the *totality* of black experience, the experience of carving out an existence in a society that says you do not belong (*Emphasis Added*).”³⁷¹ Race-based medicine does not look at the totality of the African American pathological experience rather it irrationally uses drugs as a quick fix toward health equity.

In a social context, African Americans are still in an inescapable degradation. African Americans know their physical blackness was constructed never to be an appropriate form of human existence. The construction of African Americans being less human is the affirmation of whatever is considered degrading, because the definition of

³⁷⁰ De La Torre, Miguel A. *Doing Christian Ethics from the Margins*. Maryknoll, N.Y.: Orbis Books, 2004, 26.

³⁷¹ Ibid., 25.

orthodoxy is in fundamentals of “whiteness.” Race-based medicine reasserts the negative ideologies and theologies of skin color. As Dr. Delores S. Williams mentions, “The Bible and white interpretations of biblical stories also fed into this debasement of blackness and black people.”³⁷² Due to harmful social and biblical interpretations, blacks call themselves beautiful, because a racist society and churches made “blackness” ugly. Blacks glorify blackness because it is despised. The black experience is catching the spirit of blackness and loving it. It is the powerful tool of self-love and affirmation that sustained the value of black skin and black self-worth.

In a political context, Dr. De La Torre describes, “If the dominant culture continues to be the sole interpreter of moral reality, then its perspectives will continue to be the norm by which the rest of society is morally judged.”³⁷³ The framework of “law and order” is the stability of the status quo. This results in putting blacks in a political box by “staying in their place”, and the “moral” and “political” obligation “whiteness” to be a social standard. The black experience is more than dealing with racism. It means blacks are empowered to make decisions about themselves and have the autonomy to fulfill their decisions and desires. Race-based medicine hinders autonomy by restricting racial groups’ choices and identification.

Race was a means of identification. It was to classify and separate one group from the next. As Dr. Cornell West states, “Identity has to do with protection, association and recognition. People identify themselves in certain ways in order to protect their bodies,

³⁷² Williams, Delores S. *Sisters in the Wilderness: The Challenge of Womanist God-Talk*. Maryknoll, N.Y.: Orbis Books, 1993, 91.

³⁷³ De La Torre, Miguel A. *Doing Christian Ethics from the Margins*. Maryknoll, N.Y.: Orbis Books, 2004, 12.

their labor, their communities, and their way of life.”³⁷⁴ The fact that the black community, at one point, did not have a collective sense of self made it easier for those individuals that were anti-black to take advantage of them. The manipulation of the African American community’s social protection was a result of lost recognition and association. One might assume race-based medicine promotes recognizing disadvantaged groups affected by health inequity. However, it does the complete opposite. Race-based medicine continues the racist language of labels and stereotypes exclusively associating medical conditions and diseases to a racial group. The development of black power (African American self-determination as agents of social and political change) challenged the ideologies of race-based medicine by empowering the black community to define its own place and value. The use of black power and black theology developed a positive perception of being black.

The concept of black power brought self-esteem and self-respect to the African American community. Black power was an efficient means of participatory theology and bioethics in the black community. As Dr. Lisa S. Cahill suggests, “Theological bioethics as participatory must explicitly link religion and theology to practices and movements in civil society that can have a subversive or revolutionary impacts on liberalism, science, and the market.”³⁷⁵ Black power was influential because it enabled African Americans to take a self- assessment of their value. It was evident that race-based medicine does not value and label the African American, but if African Americans do not value themselves; than they truly do not have self-value. Black power teaches you that true value comes from oneself not others and black theology brought spiritual relevance to self-value. Both

³⁷⁴ West, Cornel. *Race Matters*. New York: Vintage Books, 1994, 501.

³⁷⁵ Cahill, Lisa Sowle. *Theological Bioethics*. Washington, DC: Georgetown University Press, 2005, 39.

were powerful mechanisms that kept African Americans sane and gave hope for temporal and eternal justice.

Black theology defines empowerment and justice of African Americans in an environment that is rooted in and thrives on oppression. However, black theology is not solely based upon what whites did to blacks but a symbol of justice for everyone who are oppressed. It is an extension of progressive action for anyone who are victims of the status quo. Black theology is participation theology that “holds up as an explicit goal, the creation of connective practices among interlocutors in order that shared social practices may be transformed in light of religiously inspired ... visions and values.”³⁷⁶

Blacks replaced dehumanizing identifications with the belief that they were created by the same God with equal value. Black theology condemns race-based medicine because it separates racial groups as different beings through the construction of race. It does not matter what skin color you are we are all human beings and come from the same God. Race should not determine the proxy of disease. Therefore, it is the African American’s human right to be treated with dignity and respect by the virtue of their creation.

The historical accumulations of racism, xenophobia, segregation, slavery, and a perverted form of Christianity tainted race. Blacks lived through serious consequences, oppressive conditions, and unimaginable experiences. Thus, making black skin a relevant physical trait based on historical experience. African Americans comprehend their identity by connecting these symbols of the past. It is through the black experience, good and bad, that shaped who was considered black and what black signifies. Race-based

³⁷⁶ Cahill, Lisa Sowle. *Theological Bioethics*. Washington, DC: Georgetown University Press, 2005, 38.

medicine reasserts racist ideologies in medical discourse. As a result, labels oppress minority communities, minorities' personhood is challenged, and the adequate alleviation of health inequity will not be addressed.

Identity

As discussed in chapter one, race is a social and historical construction that corrupted social ideologies in the United States. This was evident due to xenophobic actions. Xenophobia is an unreasonable fear, distrust, or hatred of strangers, foreigners, or anything perceived as foreign or different. This was the behavior of the United States and its European influence. European society did not adequately comprehend African and Caribbean societies and as a defense mechanism fear and lack of understanding became a reality. So as a result, "white" society used identity as a comfort zone, as a social spectrum, in this new world to emphasize their self-worth, and to comprehend difference.

The self-worth of "whiteness" evolved into a repulsive and conceited pride called white supremacy, which resulted in Jim Crow laws, and the unscientific and irrational declaration of Social Darwinism, which led to the biological, medical, and social degrading of minorities. As Cornel West states, "Oftentimes they [blacks] were not welcome in white suburbs, and they weren't being recognized. Their talents and capacities were debased, devalued and degraded."³⁷⁷ These elements and principles of thought brought about the social construct of race created by the fear of human difference.

³⁷⁷ West, *Race Matters*, 501.

Blackness is not a certainty through genetics, fundamental human difference, or biological traits but an actuality through historical experience. Through the racial discourse, racial denigration slowly developed. This persuasion quickly developed in the early years of the United States. White social development became the standard (the idea of normalcy) in American society. Thus, making race Americanized socially and historically. Blackness became an historical signifier of suffering and social injustice.

When we define an object, we explain or identify the nature or essential qualities of the object. As long as, the object is immutable or unchangeable, the definition is the same. For example, we know that a tree is a plant having a permanently woody main stem or trunk, ordinarily growing to a considerable height, and usually developing branches at some distance from the ground. On the other hand, if the tree's trunk, branches, and leaves change; do we still call it a tree? If the object possesses differences but the essential qualities are the same, how will one conclude on monotony? This is the same question about race. We are all human. External qualities are different but humanness and value is no less due to external differences.

Jeremiah 13:23 states, "Can Ethiopians change their skin or leopards their spots? Then also you can do good who are accustomed to do evil." In context, the prophet Jeremiah is proclaiming to Judah that they cannot change their transgressions. As a result, they will have dire consequences. The wording of this text demonstrates perceptions of one's appearance. In contemporary understanding, Ethiopian should not be associated with the African country and its citizens. The term Ethiopians or Cushites (in other translations) refers to the color of a group of people's skin. It means blackness, dark or

black skinned, Negro, or burnt skin complexion.³⁷⁸ Misinterpretation of this scripture was used as a scientific biblical reference to assert the fatalism of racial traits and manipulated human beings as different racial entities.³⁷⁹ Regardless of what skin color you possess, it does not exclude you from being a viable human being.

The object as we know as the human person has changed through self-manipulation. As Theologian Karl Rahner states, “Self-manipulation means that today man is changing himself.”³⁸⁰ Due to enhanced medical technology, a person can alter or change external qualities. Some examples are a person born a male can change into a female and vice versa, a veteran who lost limbs in a war can receive prosthetic limbs, differently abled individuals with mental challenges, and individuals with different hues of skin color. All these examples define the human person. The differences do not diminish any individual from their humanness.

Difference compliments the complexities of being human. Personhood is a relative. Extrinsic qualities can never provide a concrete definition, because they are unique and will change with time. The internal sense of humanity is invariable regardless of time. Self-manipulation happens when one changes the essence of who they are to conform to ideologies, dogmas, theologies, and social constructs that reject the uniqueness of their humanity. Hence, race-based medicine does not compliment progressiveness in society. Rather, it sustains the harmful notions about race. The relativism of what America conceived as “race” is also evident in what we classify as the

³⁷⁸ Sadler, Rodney S. “Can A Cushite Change His Skin? Cushites, “Racial Othering” and the Hebrew Bible.” *Interpretation* 60, no. 4 (2006), 390.

³⁷⁹ Washington, *Medical Apartheid*, 226.

³⁸⁰ Dych, William V. *Karl Rahner*. A&C Black, 2000, 134.

human person. The definition of a human being and race in our present age is far more complex than what we thought and described it to be.

Humanity, as the being free in relation to God, is in a most radical way empowered by actions and choices. This freedom of choice or free will was exploited through Adam and Eve's disobedience eating from the Tree of Knowledge of Good and Evil (cf. Genesis 3). Their disobedience led to the self-manipulation of themselves into objects that were set apart from God's original intentions. Before the fall of mankind, Adam and Eve were in genuine assurance of who they were but after the fall their God given essence was diminished. In the human race's compromised essence, we began to insert self-manipulation in the form race. We became self-righteous believing we are more valuable than our human counterparts. Such egotistical realities perverted and constructed race by the use of monogenism and polygenism in biblical scripture.

Misunderstandings of Scripture

Based out of the Genesis etiology accounts, monogenism and polygenism were two schools of thought. Monogenism is the theory that the human race has descended from a single ancestral type. Polygenism suggests the human race has descended from two or more ancestral types. Polygenism is the belief ancestors from Adam were white individuals and other minorities were called pre-Adamites meaning before Adam. In 1520, the idea of polygenism first came from Swiss physician Paracelsus who believed that Adam's ancestors inhabited a small region in the earth and minorities came from a

completely different origin.³⁸¹ The notion was God's first creation (minorities) was not sufficient but God's second creation Adam and Eve (whites) was the perfect representation of creation. As Dr. Naomi Zack mentions, "polygenic theory of distinct origins for different races was used to argue that Africans, Asians, and Indians were permanently inferior to whites. That is, both the monogenicists and polygenicists began with the premise of white superiority, but differed about its nature."³⁸² Numerous debates on human geography and human origins were apart of monogenicists and polygenicists dialogue.

In 1591, Italian philosopher Giordano Bruno did not agree that black individuals came from the same origin of Jews. In 1655, a French protestant named Isaac de La Peyrere suggested pre-Adamite races produced Africa, Asia, and the New World.³⁸³ New York lawyer William Frederick Van Amringe was cautious of pre-Adamite ideas in his 1848 publication called *Investigation of the Theories of the Natural History of Man* but believed in multiple human species of different creative origins.³⁸⁴

In the early nineteenth century, a major figure in the study of skulls was Dr. Samuel George Morton. Morton collected and studies over 600 skulls to discover "that a ranking of races could be established objectively by physical characteristics of the brain, particularly by its size."³⁸⁵ Based on his studies, Morton published *Crania Americana*

³⁸¹ Graves, Joseph L. *The Emperor's New Clothes: Biological Theories of Race at the Millennium*. New Brunswick, N.J.: Rutgers University Press, 2001, 25.

³⁸² Zack, Naomi. *Philosophy of Science and Race*. New York: Routledge, 2002, 14.

³⁸³ Graves, *The Emperor's New Clothes*, 26.

³⁸⁴ Livingstone, David N. *Adam's Ancestors: Race, Religion, and the Politics of Human Origins*. Baltimore: Johns Hopkins University Press, 2008, 94.

³⁸⁵ Story, Kaila A. "Racing Sex-Sexing Race: the Invention of the Black Feminine Body." *Imagining the Black Female Body: Reconciling Image in Print and Visual Culture*, edited by Carol E. Henderson. New York: Palgrave Macmillan, 2010, 36.

(1839) and *Crania Aegyptiaca* (1844). Both of Morton's studies influenced the idea of monogenism and racial ranking. As Dr. Kaila Adia Story asserts, "European as well as American scientists not only were 'scientifically' invested in the conviction of African inferiority but also created an ideology outlay with this assumption, due to their capitalist and social interests."³⁸⁶ The pre-Adamite ideology was used to prove human variation.

Physician John Mason Good believed that different groups adapt to geography and were products of human variations. He claimed, "The first fall of man... did not take place till one hundred and twenty-nine years after the creation of Adam."³⁸⁷ Good's suggestion implies that the fall of man was due to the consequences of the pre-Adamites. Polygenicist David Hume and Naturalist Georges Buffon believed blacks were apart of inferior races but could improve being in the proper environments.³⁸⁸ Swiss naturalist Harvard Louis Agassiz's two papers in the 1850 *Christian Examiner* proposed there are distinct zoological zones or provinces in which the creator placed discrete species and in his *Naturphilosophie* he asserted that each race had its point of origin.³⁸⁹ Agassiz did not believe in the Genesis account but suggested races were made for specific places.

Other individuals that promoted human variation were Boston medical naturalist Samuel Kneeland who produced an 84 page intro in his 1848 *The Natural History of the Human Species*.³⁹⁰ Arabic scholar and lexicographer Edward William Lane believed the pre-Adamite race existed during and after Adam and the Adamites' race were divinely created and mated with pre-Adamites to produce diversity of racial types. Baptist layman

³⁸⁶ Story, *Imagining the Black Female Body*, 37.

³⁸⁷ *Ibid.*

³⁸⁸ *Ibid.*, 30-31.

³⁸⁹ *Ibid.*, 95.

³⁹⁰ *Ibid.*, 97.

and physician George Moore attributed race to climate in his 1866 book *The First Man and His Place in Creation* and physical anthropologist James Cowles Prichard proclaimed a civilization as a race-forming factor that stimulated variation by the process of domestication.³⁹¹ Clinical psychologist Robert Dunn held the same belief that the environment modified skin color, hair and character. Polygenism was a means to justify and explain racial etiology and racist treatment but such claims are not consistent with the historical and literary milieu of scripture.

The 1988 *Nature* article written by Berkeley scientists Dr. Mark Stoneking, Rebecca Cann, and Allan Wilson revealed unprecedented insight into the etiology of humanity. Their research uncovered the maternal ancestor of existing humans.³⁹² This figure was named “Mitochondrial Eve” or “African Eve.” Based on the article, Africans are the most diverse and Asians the next across all functional regions, which suggests that “Africa is a likely source of the human mitochondrial gene pool.”³⁹³ In the process of research, the Mitochondrial DNAs from 147 people were drawn from five geographic populations had been analyzed by restriction mapping. All of the mitochondrial DNAs came from one woman who is postulated to have lived about 200,000 years ago, in Africa. All the populations were examined except the African population to have multiple origins, implying that each area was colonized repeatedly.³⁹⁴

Such a discovery brings serious reservations about Paracelsus’ racial pre-Adamite claims. To be fair, we have the benefit of science and technology that was not even

³⁹¹ Livingstone, *Adam's Ancestors*, 117-119.

³⁹² Oikkonen, Venla. "Mitochondrial Eve and the Affective Politics of Human Ancestry." *Signs* 40, no. 3 (2015), 748.

³⁹³ Stoneking, Mark, Rebecca L. Cann, and Allan C. Wilson.. Mitochondrial DNA and human evolution. *Nature* 325 (6099) (1987), 33.

³⁹⁴ *Ibid.*, 32.

imagined in the early sixteenth century. However, what this late twentieth century discovery challenged was the perceived “white washing” of biblical figures which has been ingrained in European and American biblical narrative for centuries, excluding positive biblical perceptions of African representation. The book of origins known as Genesis illustrated key racial passages that influenced racial discourse in American society.

Genesis 4:1-15 illustrates the first children in canonized scripture Cain and Abel. It appears that the first sexual act occurs outside of the garden, but this is not entirely clear. The name Cain (*qayin*) meaning “I have produced” (*qaniti*). Cain, the first older brother in the scriptures, is initially a tiller of the ground, like his father (Adam), continuing the troubled relationship between man (*‘adam*) and the ground (*‘adamah*). This difficulty is based from his father’s disobedience in the Garden of Eden (cf. Genesis 3:14-19). Abel, the younger son, like King David in his youth was the keeper of the sheep, which had less prestige than farming.

Genesis 4:3-7 continues with Yahweh’s interaction with Cain and Abel’s offering. The only difference between the values of the two sacrifices is that Abel offers the “firstlings,” in contrast to Cain who offers the fruit (but not the first fruit). The text implies that Abel gave the freshest offering, and Cain gave God the leftovers.³⁹⁵ Cain’s interaction with Abel resulted in Abel’s death. When Yahweh asked Cain, Where is your brother Abel? Cain’s profound response was, “Am I my brother's keeper?” This is the first question that a human being had ever asked God in the biblical canon. Cain’s answer

³⁹⁵ Gunn, D. M., and Danna Nolan Fewell. *Narrative in the Hebrew Bible*. New York: Oxford University Press, 1993, 15.

has become a question of arrogance, selfishness, and disownment. This question comes from the same lips that shared the same milk from their mother Eve's breast, and now the same thing that sustained them, the milk from the same source, which bounded them together in their brotherhood, has now turned sour. Sour milk tainted by a selfish and jealous mentality. The pain caused by Cain's selfishness and jealousy caused him to kill his brother.

In an American context, the realities of fear (xenophobia) are the elements that divide humanity. It makes us think that one is racially better or worse off than our fellow human equals. God created us and shaped us in his image (*imago dei*), and breathed into us the spirit of life. As humans, we tainted our God given skin colors, and react just like Cain. The source of milk or the human spirit in us that was supposed keep us in unity we have made sour. As a result, we end up asking the question "Am I my brother's keeper?" Am I responsible for my brother or sister regardless of what they look like and what social context they are in? We respond with attitudes of mythical racial pride.

In verses 10 through 15, God and Cain's had a discussion,

And the Lord said, 'What have you done? Listen; your *brother's blood is crying out to me* from the ground! And now you are *cursed from the ground*, which has opened its mouth to receive your brother's blood from your hand. When you till the ground, it will no longer yield to you its strength; you will be a fugitive and a wanderer on the earth.' Cain said to the Lord, 'My punishment is greater than I can bear! Today you have driven me away from the soil, and I shall be hidden from your face; I shall be a fugitive and a wanderer on the earth, and anyone who meets me may kill me.' Then the Lord said to him, 'Not so! Whoever kills Cain will suffer a sevenfold vengeance.' And the Lord put a *mark on Cain*, so that no one who came upon him would kill him (*Emphasis Added*).

The polygenistic hermeneutics of this text asserted that Cain was cursed with the mark of black skin. As Dr. Charles B. Copher suggests, “Cain as an ancestor of black peoples is the pre-Adamite view.”³⁹⁶

Ancient rabbis developed two interpretations about Cain’s blackness. Cain became black as a result from the smoke of his sacrifice or Cain’s face became black as a result of hail.³⁹⁷ This interpretation is extremely disjointed. The text illustrates Cain’s response was fearful believing that his punishment was unbearable and his life would be in danger. In response, God gave Cain a mark of protection to prevent Cain to endure physical harm or threat. The text does not inherently illustrate anything about Cain’s mark being a change in his skin color. Since the twelfth century, interpretations of Cain’s change in skin color have been associated with European hermeneutics.³⁹⁸

Similar to his father Adam, Cain’s curse was from the earth or ground. Cain’s mark was a bestowal of grace dealing with his punishment not the punishment itself. Furthermore, the text demonstrates that God found out about Abel’s murder not through Cain confessing but through a disembodied cry for justice.

God’s profound statement to Cain echoes even if the body is not there blood “cries out” for one’s defense. Abel’s blood stains on the ground were his identity. It was visual evidence of Cain’s immoral act. The countless bloodshed of black bodies by the institution of slavery, Jim Crowism, lynchings, medical experimentations, race riots, and

³⁹⁶ Copher, Charles B. “*The Black Presence in the Old Testament. Stony the Road We Trod: African American Biblical Interpretation*,” edited by Cain Hope Felder. Minneapolis: Fortress Press, 1991, 149.

³⁹⁷ Ibid., 148.

³⁹⁸ Ibid., 149.

police brutality are not forgotten. Throughout the centuries, I believe that God has heard “black blood” crying out for justice. Black ancestors are gone but their blood still speaks.

Genesis 9:18-27 illustrates the experience of Noah’s nakedness and the curse of Canaan. I suggest three important elements in this text. First, Noah’s nakedness, second, covering or hiding Noah’s nakedness, and third turning away or ignoring Noah’s nakedness. Noah’s nakedness is interchangeable with sin (transgression). There is also a sexual element in this text but I will digress from this topic since my focus is race. The Ark was a symbol of the new world and a fresh start but Noah and Ham tainted such new beginnings.

Noah abused his power and free will by excessive drinking. Instead, of turning away immediately and covering Noah, Ham saw Noah in a state he was not supposed see him in, which violated two norms highly stressed in the Tanakh and Rabbinic Judaism, bodily modesty and the norm to honor and respect one’s parents (cf. Exodus 28; 20:12, Leviticus 19). Out of guilt Ham called Shem and Japheth who walked backwards to cover Noah. Shem and Japheth walking backwards is a suggested representation of stagnating human-kind’s progress.

Genesis 9: 24-27 records the curse of Canaan which has been notoriously and inappropriately used as a demeaning interpretation of race. The transgression of American Church history was the misappropriation of this text. As the Rev. Dr. Katie G. Cannon mentions, “Central to the whole hermeneutical approach was a rationalized biblical doctrine positing the innate and permanent inferiority of Blacks in the

metonymical curse of Ham.”³⁹⁹ The curse of Ham or Canaan was used as biblical justification to enslave black folks, who were viewed as the “Sons of Ham.” Through polygenistic interpretation, Ham and Cain’s descendants were revealed by their black skin as a physical representation of both curses.

Similar to Noah being the father of nations in the new ancient world, the fathers of the proposed new world called America perverted their free will and abused their power. American forefathers enforced excessive inhumane and unethical treatment of those from the Africana descent. As Dr. Sylvester A. Johnson mentions, “The Hamitic was unyieldingly wed to the institution of slavery because American slavery was preeminently racial. Its victims were exclusively the folk whose existence was already popularly explained in terms of Hamitic descent.”⁴⁰⁰ As a result, millions of black folks could not reach their full human potential. American nakedness (transgression) permeated through generations of injustice.

Instead of exposing one’s history of racial relations, America brought its “Shem and Japheth” type of response that “God would ‘enlarge’ Japheth, putatively by ensuring that whites would succeed ‘Shemites’ and become bearers of religious truth and Ham was to have serve them both.”⁴⁰¹ America’s actions of denial and the status quo walking backwards, hindering progress, covering up its transgressions through filtered media and educational structures that hide and skew information, knowledge, and history. Then blame the state of black individuals on themselves not acknowledging historical domestic

³⁹⁹ Cannon, Katie G. “*Slave Ideology and Biblical Interpretation. The Recovery of Black Presence: An Interdisciplinary Exploration: Essays in Honor of Dr. Charles B. Copher*,” edited by Charles B. Copher et al. Nashville: Abingdon Press, 1995, 121.

⁴⁰⁰ Johnson, Sylvester A. *The Myth of Ham in Nineteenth-Century American Christianity: Race, Heathens, and the People of God*. New York: Palgrave Macmillan, 2004, 70.

⁴⁰¹ Ibid.

neglect on black societies. Simultaneously, America's face turns away, because it does not want to see its own neglect on black lives. Such realities make the survival of blacks possible through the use of black theology.

Contrary to polygenetic views, black theological interpretation of Hebrew scripture illustrated endearing situations about figures of African descent. For example, Numbers 12:1-15 is an account of Moses and his Ethiopian or Cushite wife. Aaron and Miriam had reservations about Moses marrying a dark skinned woman. As a result, God punished Miriam with leprosy as white as snow (v.10). This text has dualistic meanings. First, whiteness suggested as a negative symbol or a curse. Second, blackness represented a gain of class and status.

The text spurs interest in the explicit phrase "leprous, as white as snow." For example, Isaiah 1:18 states, "Come now, let us argue it out, says the Lord: though your sins are like scarlet, they shall be like snow; though they are red like crimson, they shall become like wool." As Dr. Randall C. Bailey asserts,

The interpretation rests upon the understanding that in the Hebrew canon to be white as snow is a curse. Being made white as snow in Isaiah is often mistranslated. For Bailey, "Such is seen in the oft-mistranslated Isaiah 1:18. In this verse, part of a judgment speech, the charge begins with the word 'm, 'if.' Thus, the prophet proclaims, 'Come to judgment, if your sins are as scarlet [= negative], then they will be made white as snow [= the punishment]. Since all other instances of 'm found in this unit are read as 'if,' there appears to be no reason, other than the desire to keep the phrase 'white as snow' as a blessing, to translate it here as 'contrary to fact/though,' as do most exegetes. The punishment for complaining about Cushites as a means of status makes her the exact opposite of the Cushite, white as snow."⁴⁰²

⁴⁰² Bailey, Randall C. "Beyond Identification: The Use of Africans in Old Testament Poetry and Narratives." *Stony the Road We Trod: African American Biblical Interpretation*, edited by Cain Hope Felder. Minneapolis: Fortress Press, 1991, 179-180.

God's response illustrated Miriam's important social standing of that time. Dr. Renita J. Weems asserts, "Her reputation as a poet and songstress (Exodus 13:21), combined with her anointing as a charismatic leader (Micah 6:4), must have made Miriam a figure to be reckoned with by the Hebrews, especially among women."⁴⁰³ Also, Jeremiah's account illustrated a positive narrative of a Cushite named Ebedmelech who rescued the prophet Jeremiah (cf. Jeremiah 38:7-13).

The New Testament mentions positive stories of ancient black individuals. Simone of Cyrene, helped Jesus carry his cross (cf. Mark 15:21). Cyrene was an ancient city in Libya, Africa. Simon is suggested to be the model disciple because he "literally took up the cross" to assist Jesus, which deemed his action "justifiable under the rules of Greco-Roman rhetoric."⁴⁰⁴ Even John of Patmos described Jesus Christ with white hair like lamb's wool (nappy hair) and feet like polished brass (cf. Revelation 1:14-15). Jesus was not a white individual but came from African and Asian ancestry.⁴⁰⁵ Scriptures like these were used by the black preacher to encourage anti-black usage of scripture. The Black theology in scripture is a great tool for minority patient empowerment.

Biblical and Medical Narrative: Empowerment and Justice

In regards to race-based medicine, scripture can be used as effective aid by the illness narratives in the gospels. New Testament illness narratives are the experiences of Jesus Christ interacting with individuals or groups that are suffering from illness, disease,

⁴⁰³ Weems, Renita J. *Just a Sister Away: A Womanist Vision of Women's Relationships in the Bible*. San Diego, Calif: LuraMedia, 1988, 72.

⁴⁰⁴ Sanders, Boykin. "In Search of a Face for Simon the Cyrene." *Stony the Road We Trod: African American Biblical Interpretation*, edited by Cain Hope Felder. Minneapolis: Fortress Press, 1991, 54.

⁴⁰⁵ Hopkins, Dwight N. *Down, Up, and Over: Slave Religion and Black Theology*. Minneapolis, MN: Fortress Press, 2000, 263.

and deformity. As discussed in the three previous chapters, race-based medicine excludes and limits the holistic possibilities of care for minority patients. I will use the illness narratives of the leper in Galilee (cf. Mark 1:40-45), the man with a withered hand in a synagogue at Capernaum (cf. Mark 3:1-7), and the woman with the issue of blood at Capernaum (cf. Mark 5:24-34)⁴⁰⁶ as a means of minority patient empowerment.

Leper in Galilee

Mark 1:40-45 illustrates the first time Jesus heals from the ancient disease of Leprosy. Other accounts of leprosy were in the gospel of Luke (cf. Luke 5:12-14; 17: 11-19). The text does not specifically mention where Jesus was. Jesus enters this unknown village and comes across a leper who approaches him. He begs to be cured from his leprosy.⁴⁰⁷ Leprosy is a contagious disease that affects the skin, mucous membranes, and nerves, causing discoloration and lumps on the skin and, in severe cases, disfigurement and deformities. According to the *Oxford Dictionary of English*, leprosy is now mainly confined to tropical Africa and Asia. In biblical times, there was no treatment for leprosy. Today, leprosy can be cured with different form of antibiotics.

In a begging posture, he knelt down and said, “If you choose, you can make me clean.” This was significant because the leper approached Jesus. Lepers lived a life being perceived to have no dignity and value. They did not receive any sympathy from the community and society they existed in. For years, they saw individuals come and go that

⁴⁰⁶ The synoptic gospel of Mark is the earliest of the canonized gospels which is a personal preference of usage.

⁴⁰⁷ Biblical literature refers to this man’s disease as leprosy. It is possible that this man had another disease. Since the pathology and diagnosis of diseases were not well known in ancient times, the word leprosy was used interchangeably to describe a condition not discovered or fully understood. To simplify, I will use the term leprosy for this man’s condition.

could not help them in their leprous condition. They were often feared to cause a major epidemic, which would threaten the survival of ancient society. That is why most lepers kept their distance because Jewish law required them to stay away from non-leprous individuals to prevent the spread of disease and to prevent the defiling of sacred buildings like the Tabernacle and religious gatherings (cf. Leviticus 13:46; Numbers 5:2-3).

Yet, this individual broke all social and religious norms to be cured from his disease. Jesus, being a Jewish Rabbi, also broke Jewish law by interacting with him. Jesus had empathy on him and healed the man. Jesus was not concerned with the social and religious etiquette. He acknowledged the humanity of the individual. In humility, Jesus urged the man not to report his holistic experience. Of course, the man who had been cured from his disease told everyone he could. He received his autonomy, value, and integrity with one experience of ethical care. He was empowered to thrive in a society that ostracized him for so long because of the peculiarity of his skin.

Similar to the leper's experience, the minority patient had been devalued because of their skin. As described in chapters one and two, black skin was viewed as a threat to American society. It was an epidemic associated with sickle cell anemia and other diseases. Blacks were forced to keep their distance away from whites because of what they looked like. I suggest black skin was (and still is) the stigmata of medicine.

Stigmata is the term used for the marks of Jesus Christ's crucifixion, which were the marks on Christ's head (crown of thorns), hands and feet (nails), and side (spear). The Apostle Paul mentions that he bears the marks of Christ (cf. Galatians 6:17). Stigmata refers to the suffering of Jesus Christ's crucifixion and victory of his resurrection. In

contrast, black skin as “medical stigmata” symbolizes the suffering of black people in unethical clinical treatment and the victory of overcoming such monstrosities.

It is unfortunate that health disparities and mediocre medical treatment continue to affect African Americans. As Dr. Emilie M. Townes suggests, “The US medical system suffers from interstructured paternalism and racism. One of the foundational aspects of this problem is the way the majority of doctors receive their training and the lack of rigorous and ethically responsible clinical trials that include racial-ethnic men and women and White women.”⁴⁰⁸ As I addressed in chapter three, clinical solutions can start with physician training in cultural competency, empathy and awareness. However, this was not a reality for African Americans in most of the twentieth century. African Americans had to develop their own means of health and wellness. Blacks built adequate medical care through the legacy of the Black Panther Party.

The Black Panther Party (BPP) was notorious for its brash response to a racist society. The organization was widely known for its political activism but the BPP was also instrumental in health advocacy and outreach. BPP’s advocacy was reflected through the People’s Free Medical Clinics (PFMCs). The clinic’s goal was to have “completely free health care for all black and oppressed people.”⁴⁰⁹ PFMCs operated through community based medical clinics and a health network of professionals.

For most of the twentieth century, it was very difficult for blacks to get medical care because public hospitals were often overcrowded and lacked adequate staff and private hospitals were too expensive. The PFMCs provided the means for African

⁴⁰⁸ Townes, Emilie Maureen. *Breaking the Fine Rain of Death: African American Health Issues and a Womanist Ethic of Care*. New York: Continuum, 1998, 45.

⁴⁰⁹ Nelson, *Body and Soul*, 4.

Americans to get efficient care in their local communities. Individuals with serious medical needs or surgery were suggested to go to doctors and medical facilities that would be able to assist. The leper's story demonstrated Jesus Christ's empathy and solidarity toward the leper while completely disregarding societal norms and rules. PFMCs philosophy was "Christ like" bringing humanism within medical care. It was empathic care inclusive of socioeconomic status and acceptance. PFMCs asserted health care as a human right and not a commodity.

The Party's PFMCs rebuild the patient-physician relationship in the black community. Historical perceptions of American medicine reflected the symbol of the white coat as a symbol of suffering and even death in communities of color. However, the important element of trust for blacks in the medical clinic was restored through PFMCs. As Sociologist Dr. Alondra Nelson states,

The white coat of medical science could have a different connotation in black communities. Because the Party worked with populations that historically had not had regular contact with medical professionals, the white coat, worn by *trusted experts*, could be a welcome sign of long sought access to quality healthcare as well as an emblem of the potential *excesses of medical power* (*Emphasis Added*).⁴¹⁰

When the black community started to trust their medical professionals they began to invest into a cause that was genuinely invested in them. African Americans finally had the opportunity to go to someone who looked like them and understood black life. PFMCs gave blacks the authority to own their medical care and empowered them to take charge of their health.

⁴¹⁰ Nelson, *Body and Soul*, 84.

All BPP clinics had examination tables, offered primary, preventive, and dental care, collaborated with medical professionals, conducted protocol for the spread of diseases, relied on donations for supplies and labor, and ran an ambulance EMT unit, which was provided by businesses, churches, and BPP's supporting organizations.⁴¹¹ The clinics had grocery giveaways for individuals that did not have the means to buy food. PFMCS promoted health literacy and education. It also advocated for self-help care or self-care which trained women to do gynecological self-examinations and self-help testing for individuals with sickle cell anemia.⁴¹²

Like the leper's enthusiastic response of his physical renewal, African Americans could not lay stagnant on their medical progress. PFMCS grew to a national level and influenced medical discourse. Blacks had to simultaneously continue to take charge of their health and be empowered to be active agents of change in American healthcare. PFMCS dwindled away in the 1970s but its influence remains strong today through the health advocacy of the NAACP, Association of Black Cardiologists, the Congressional Black Caucus, the National Baptist Convention USA Inc.'s Health Outreach Prevention Education (HOPE) outreach to name a few.

The Man with a Withered Hand

Mark 3:1-7 records Jesus Christ's interaction with a man that had issue with his hand. The Markan account described the condition of the man's hand as withered. It is obvious that we cannot precisely diagnose what ailment this man had. However, the man's condition can be suggested to be similar to Hand Atrophy (deterioration of

⁴¹¹ Nelson, *Body and Soul*, 84-90.

⁴¹² *Ibid.*, 89-90.

muscles), severe Carpal Tunnel Syndrome (nerve issues that result in stiffness in hand and fingers), or a symptom of Cerebral Palsy (clamping of the hand).

The text described Jesus entered in a synagogue. His immediate attention was to a man with a withered hand. This event was on a sacred day, the Sabbath. Jewish law did not allow Jesus to perform any type of work. The Pharisees watched to see what Jesus' reaction was going to be. He either would not cure the man to conform to Jewish law or cure the man against Jewish law. The Pharisees took the Jewish Sabbath law very seriously and would reprimand Jesus if he broke the law. Jesus told the man who had the withered hand, "Come forward." While the Pharisees watched, Jesus told them, "Is it lawful to do good or to do harm on the Sabbath, to save life or to kill?"

The Pharisees had no reply to Jesus' question. Jesus was angry about the Pharisees' unempathetic response and said to the man, "Stretch out your hand." The man stretched out his hand and was restored. The Pharisees wanted to punish Jesus for breaking the Sabbath law. Jesus retreated to the Sea of Galilee with his disciples where he was followed by spectators that witnessed the man's healing. This text demonstrates three critical evaluations. First, the synagogue a place that should practice the concept of renewal did not. Second, practitioners of presence and compassion (the Pharisees) did not show it. Third, Jesus did not follow religious correctness to heal a man with a physical issue.

A synagogue is a place of healing, renewal, growth, learning, and understanding. In contrast, a hospital should share the same attributes. It should be a place of holistic healing where anyone can practice their religious beliefs and spirituality

without being compromised. Unfortunately, the man did not experience healing. The synagogue authorities (Pharisees) were so caught up in religious correctness that they failed to see the synagogue as a place of healing and renewal. No law or idea should be able to hinder a person's renewal and oppress their human value. This man's experience has been lived through the black community through hospital care.

Chapter two mentioned the struggle of African Americans being able to get hospital care. Slave houses were the locations used to facilitate blacks medical needs. Similar to the man with the withered hand, blacks were denied access for physical restoration or treated differently because of their racial status. As Dr. Aana M. Vigen states, "Doctors may not always see the actual person in front of them but instead see only a generic representative of a larger group."⁴¹³ Blacks had to deal with racism and Jim Crow laws that prevented them to get healing in an institution that was created for such a purpose. As a result, there were not adequate hospitals to treat the black community but that changed with exceptional insight of Dr. Daniel Hale Williams.

In 1891, Dr. Williams founded the Chicago's Provident Hospital and Nurse Training School.⁴¹⁴ It was the first black controlled hospital. Black hospitals treated African Americans with respect and dignity. In other hospitals, race mattered more than class in the quality of care a patient received. The fear of medical experimentation, death, discrimination, and mistrust embolden blacks to want their own hospitals. African Americans experienced value and compassion interacting with doctors who understood

⁴¹³ Vigen, Aana Marie. *Women, Ethics, and Inequality in U.S. Healthcare: "To Count Among the Living."* New York: Palgrave Macmillan, 2006, 45.

⁴¹⁴ Gamble, Vanessa Northington. *Making a Place for Ourselves: The Black Hospital Movement, 1920-1945.* New York: Oxford University Press, 1995, 11.

black life in American society. Williams made a national declaration for black owned hospitals. Williams' decree did not only involve hospitals to care for the sick but also a means for medical education for black doctors and nurses who had very few options to practice medicine.

Kansas City General Hospital No. 2 also known as KC Colored Hospital was the first major hospital for black patients with white staff. Dr. Thomas C. Unthank founded two small private hospitals Douglass Hospital in Kansas City, Kansas in 1898 and Lange Hospital in Kansas City, Missouri, in 1903.⁴¹⁵ In 1914, Kansas City General was the first hospital to be managed by an African American when Dr. William J. Thompson became the Superintendent and Mary K. Hampton-Brown named Superintendent of nurses. Ten years later all departments had black leadership. Other black controlled hospitals included Tuskegee Institute and Nurse training school in Alabama stabled in 1892; Fredrick Douglass Memorial Hospital and Training School in Philadelphia, established in 1895; and Home Infirmary Clarksville, Tennessee, established in 1906.⁴¹⁶ In 1912, 63 black controlled hospitals existed and by 1919 almost doubled to 118.⁴¹⁷

Black hospitals thrived on the same mentality of the man with the withered hand. If anyone is at a place of hope and restoration, one's humanity and vulnerability for help surpasses any law, ideology and theology. This was the testament of black hospitals. Throughout the twentieth century, black hospitals have closed down due to financial strains and buyouts. There are only two black hospitals left. The Chicago Provident Hospital known as Provident Hospital of Cook County was taken over by the Cook

⁴¹⁵ Gamble, *Making a Place for Ourselves*, 9.

⁴¹⁶ *Ibid.*, 11.

⁴¹⁷ *Ibid.*, 3.

County Bureau of Health Services and Howard University Hospital in Washington, DC.⁴¹⁸

The Woman with the Issue of Blood

Mark 5:24-34 starts in a chaotic frenzy. A large crowd followed Jesus and surrounded him almost to the limit of asphyxiation. In the mist of the crowd, there was a woman who had been suffering from hemorrhages for twelve years. She tried many physicians and suffered painful experiences with her condition. She expunged all of her financial resources but gotten worse instead of getting better. However, this woman had hope because Jesus was in the area. When she saw him, she went through every tight space and crevice. Finally, she was close to him. She came up behind him in the compacted crowd and touched his cloak. In a determined response she said, “If I but touch his clothes, I will be made well.”

The text revealed immediately her hemorrhaging stopped and she felt in her body that she was healed of her disease. Jesus noticed someone touched him. He turned about in the crowd and said, “Who touched my clothes?” His disciples responded, “You see the crowd pressing in on you; how can you say, ‘Who touched me?’” Jesus looked around to see who touched him. The woman, who was now cured of her hemorrhaging approach Jesus reluctantly, fell down and confessed she touched him. Jesus told her, “Daughter, your faith has made you well; go in peace, and be healed of your disease.” This account was an example of Jesus, the feminist, challenging the customs and laws regarding women. As Dr. Jacquelyn Grant states, “Jesus elevated many who were at the bottom of

⁴¹⁸ Gamble, *Making a Place for Ourselves*, 194-195.

the social hierarchy to a new level of equality. This trend is especially evident in his relationship with women.”⁴¹⁹

The woman with her hemorrhage issue shared similar experiences like enslaved women with vesico-vaginal fistula (VVF). They both had medical conditions that could not be cured, suffered years with the same condition before being cured, and experienced being outcasts in a male dominated society. The bleeding woman was viewed unclean because of the Jewish law of *niddah*. This law is referred to uterine bleeding not due to injury or trauma and its usual causes are through menstruation, bleeding during pregnancy or birth (*yoledet*), ovulation, and irregular flow of blood (*zavah*). This law prohibited any contact until the bleeding stops. After seven days with no bleeding, she will be immersed in a kosher ritual bath (*mikveh*). After the woman fulfilled the requirements of *niddah* law, all interactions are permitted until she anticipates bleeding to reoccur (cf. Leviticus 15:19-30; 18:19; 20:18).

The Markan text illustrates the bleeding woman had suffered with her condition for twelve years, which means she probably did not have any physical contact and interaction with anyone for that period of time. Her financial status was dire because she had no money and was disadvantaged earning money due to her sex. In addition, she was untouchable being viewed as unclean. Similar tones of distress, comes from enslaved black women. They were viewed unfit and unclean not as a consequence of a medical condition like VVF but by the perceived inferiority of the color of their skin. Both women challenged by the societal limitations imposed on them.

⁴¹⁹ Grant, Jacquelyn. *White Women's Christ and Black Women's Jesus: Feminist Christology and Womanist Response*. Atlanta, Ga: Scholars Press, 1989, 143.

The bleeding woman endured her medical condition under many physicians. Enslaved women endured numerous conditions under physicians who physically, mentally, and emotionally took advantage of them. For example, the unethical practices of Dr. J. Marion Sims discussed in chapter two. The bleeding woman's twelve year medical tribulation is horrific but it fails in comparison with centuries of medical and civil abuses of enslaved women.

Yet, the bleeding woman and enslaved women received their healing through tenacity for change. The bleeding woman did not surrender because the crowd was compacted or tight around Jesus. Regardless of the difficulty, she found a way to position herself for healing. The bleeding woman had to overcome many obstacles in her twelve years of having hemorrhages, which shows her endurance and resolve. When the opportunity came for personal change and restoration, she took it by any means necessary.

This is an example of feminist theology. Dr. Grant mentions, "Because oppression tends to dehumanize its victims, women must reconceptualize ideas and images about themselves."⁴²⁰ The woman in the text was tired of her physical condition and social perception. She repositioned her situation from victim to victor. The woman transformed her social standing into an honorable woman of faith acknowledged by the great rabbi himself, Jesus Christ. The woman's reconceptualization was the same essence enslaved women used to influence American medicine through the importance of midwifery.

⁴²⁰ Grant, *White Women's Christ and Black Women's Jesus*, 119.

Midwifery is the procedure when a trained person assists women in childbirth. The practice of midwifery increased black women's social standing and mobility in slave communities. They were able to travel around plantations on horseback, assist with the birth of slaveholders' children, and carry news without penalty.⁴²¹ Also, black midwives were able to visit family and friends. After slavery, midwives continued to play an important role in women's and public health. They promoted maternal-child prevention by giving encouragement for women to receive prenatal and postnatal care, notified nurses when a woman gave birth, and were liaisons between poor black women and white health professionals.⁴²²

Black midwives continued to empower their communities by controlling the spread of diseases and encouraging their communities to get tested for current disease threats. For example, African American midwives helped control the spread of venereal disease and syphilis by urging pregnant women and local communities to get blood tests.⁴²³ The influence of midwifery in the black community promoted health education, literacy, prevention, and organization. The model birthing room was an unprecedented contribution of black midwives. In the early 1930s, the Mississippi State Board of Health required midwives to educate their communities about the modern standard for childbirth requirements.⁴²⁴ The midwives modern birthing room demonstrations educated future parents, communities, and health organizations on proper protocol and sterilization of a birthing room.

⁴²¹ Fett, *Working Cures*, 130.

⁴²² Smith, Susan Lynn. *Sick and Tired of Being Sick and Tired: Black Women's Health Activism in America, 1890-1950*. Philadelphia: University of Pennsylvania Press, 1995, 140.

⁴²³ *Ibid.*, 141.

⁴²⁴ *Ibid.*, 144-145.

African American midwives are the quite essential example of empowerment and health advocacy. Their knowledge and unique position in the black community pushed them to be voices of change. Black women used the profession of midwifery for social justice. They transformed their own clinical experience. Black women were the individuals being abused and mistreated in the clinical setting. As midwives, they help changed the status of black women from being recipients of maleficence and oppression to infusing a standard of care, empathy, and efficiency in gynecological and maternal care. Mark's account of the bleeding woman and black women in American medical history had to fight through encapsulating experiences being defined by sexist and racist societies. However, they overcame by achieved health advocacy and healing.

Black Church and Health Advocacy

Since its inception, the black church has been a spiritual, social, and political resource for the African American community. It has evolved into a resource of health advocacy in minority communities. The black church has progressively gotten better incorporating health education, literacy, and health partnerships within its congregation. However, there is still more work for the black church to do. This section is a reflection of past and current black church health advocacy movements and personal endeavors of health advocacy as a black clergy.

Early Movements in Black Church Health Advocacy

Historian and Sociologist Dr. WEB Du Bois established the first self-assessment of African American health in his 1906 publication *The Health and Physique of the Negro American*. It was part eleven out of an eighteen volume project dealing with

multiple areas of black life including religion, economics, class and education.⁴²⁵ The 136 page document was Du Bois' apologetic defense against social darwinism, polygenism, and eugenics' theories about race. He wanted to stress that race was not a fatalistic definition of disease. Health of human beings was the consequence of social, political, and environmental variables.

In Du Bois' landmark tuberculosis study, he retrieved vital statistics from the US Army recruiting examination records, life insurance companies, the US Bureau of the Census, and data of white working class groups in the United States and Europe, which concluded that, "Tuberculosis was not a racial disease but a social disease linked to poverty, housing conditions, and working conditions."⁴²⁶ Du Bois' research led the way for future black health initiatives and studies in secular and religious setting. Nine years later, the National Negro Health Week Movement began with the black church being its key resource.

From 1915 to 1951, the National Negro Health Week/Movement (NNHW/NNHM) encouraged blacks to advocate and address minority populations' health issues with the aptitude of health education and advocacy. The movement was founded by educator and founder of Tuskegee University Booker T. Washington. Initially, Washington's initiative was called "Health Improvement Week" an annual week of health awareness in early April but the National Negro Business League (founded by

⁴²⁵ Nelson, *Body and Soul*, 45.

⁴²⁶ Ibid., 46-47.

Washington) with the financial sponsorship of industrialist Andrew Carnegie gave Washington the necessary financial support to make it a national initiative.⁴²⁷

The United States Public Health Service (USPHS) promoted NNHW into a national black health initiative. In 1921, the USPHS started to publish the National Negro Health Week Bulletin and had the US Surgeon General Dr. Hugh Smith Cumming convene at the first NNHW annual conference in Washington, DC.⁴²⁸ In 1932, the National Negro Health Week became the National Negro Health Movement (NNHM) by the establishment of the Office of Negro Health Work through the USPHS.⁴²⁹ The NNHM was supported by local health departments, civic groups, schools, media, and businesses. However, the grass roots advocacy of NNHW was the black church.

Sunday was the most important day for NNHW. The black church is an important institution in the black community because of its influence on change and transformation. On “Mobilization Sunday,” black preachers exhorted health education sermons at worship services and church meetings.⁴³⁰ NNHW organizers urged the usage of good speakers and music to keep the black community engaged and knowledgeable on health issues. Also, Sunday was “Reports and Follow-up Day” when the black community gathered at houses of worship for large civic meetings.

NNHW’s schedule as follows: Monday “Home Hygiene Day,” Tuesday “Community Sanitation Day,” Wednesday “Special Campaign Day” which focused on specific local health needs, Thursday “Adult Health Day,” Friday “School Health Day,”

⁴²⁷ Quinn, Sandra Crouse, and Stephen B. Thomas. “The National Negro Health Week, 1915 to 1951: a descriptive account.” *Minority Health Today* 2, no. 3 (2001), 45.

⁴²⁸ Ibid., 46.

⁴²⁹ Nelson, *Body and Soul*, 30.

⁴³⁰ Quinn, “The National Negro Health,” 46-47.

and Saturday “General Cleanup Day,” which was “the large scale cleanup activities and inspection of community health campaign results.”⁴³¹ Sunday culminated activities and goals of the week. The black church was the major conduit between the NNHW and the black community. The NNHW wanted to promote the church as its key partner. In 1933, a *NNHW News* editorial declared, “The church can render a most helpful service in the Health Week Anniversary by making occasional announcements and by starting the health week proper with a good message to the church assemblies all day.”⁴³² An example of the NNHM communal success was Detroit, Michigan’s Daniel Hale Williams Health Guild.

The Daniel Hale Williams Health Guild had 200 active participants who were all black women. The members of the Health Guild used the popularity of NNHM to get support from clergy, teachers, Detroit’s Department of Health and physicians. One of the Health Guild’s major projects was, “an eight week health clinic held in black churches that immunized over 5,000 children against diphtheria.”⁴³³ Also, in Richmond, Virginia, physicians gave health education lectures at 53 black churches reaching over 10,000 people and black churches provided adult and children clinics in their houses of worship.⁴³⁴ After nineteen years under the USPHS, the move toward integration led to the dismantling of the Office of Negro Health Work and the National Negro Health Movement. Du Bois and Washington’s influence set the standard of black health advocacy and how the black church can be an integral resource in the process of health equity. Black church health advocacy continued throughout the twentieth century.

⁴³¹ Quinn, “The National Negro Health,” 46.

⁴³² Ibid., 47.

⁴³³ Smith, *Sick and Tired*, 53.

⁴³⁴ Ibid., 63.

In the civil rights era (1954-1968), African Americans continued to fight against the many systematic injustices they endured on a daily basis. Healthcare was still in the vision of the black community with The Rev. Dr. Martin Luther King as the leader of the movement. On March 25, 1966, Dr. King proclaimed, “Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”⁴³⁵ This quote was taken from his famous speech at the Convention of the Medical Committee for Human Rights held in Chicago. Black preachers have always been at the forefront for health advocacy in the black community. Another example is The Rev. Jesse Jackson.

Recent Black Church Health Advocacy

Rev. Jesse Jackson’s black church advocacy was in the prevention of HIV/AIDS. Rev. Jackson used slogans, health education materials, and ideas for policy reform.⁴³⁶ The push for HIV/AIDS awareness was successful incorporating slogans and health education in sermons and youth programs. Another HIV black church partnership was with the Churches United to Stop HIV (CUSH) established in 1999. CUSH was based out of Broward County, Florida. CUSH’s objective was, “to include training faith-based leaders and congregations to develop HIV educational programs, outreach and referral services, and support programs for infected individuals and others affected by the epidemic. To meet these objectives, CUSH staff created a training manual, brochures and palm cards.”⁴³⁷

⁴³⁵ Peterson, Eric, and Clyde W. Yancy. “Eliminating racial and ethnic disparities in cardiac care.” *New England Journal of Medicine* 360, no. 12 (2009), 1172.

⁴³⁶ Pinn, Anthony B. *The Black Church in the Post-Civil Rights Era*. Orbis Books, 2002, 96.

⁴³⁷ Agate, Lisa L., D'Mrtri Cato-Watson, Jolene M. Mullins, Gloria S. Scott, Vanice Rolle, Donna Markland, and David L. Roach. "Churches United to Stop HIV (CUSH): a faith-based HIV

CUSH was not a health initiative exclusively led by the black church. Black churches were included with churches from all socioeconomic backgrounds. CUSH has provided HIV prevention to over 32,000 people, trained for over 2,850 faith leaders, and provided risk assessments for over 1,000 people, counseling and testing for over 825 participants and technical assistance for 48 churches.⁴³⁸ African American Immunologist Pernessa C. Seele developed an organization called the “Balm in Gilead” to assist black churches developing programs to efficiently educate congregations on AIDS.⁴³⁹

In regards to drugs, the National Conference on the Black Family/Community and Crack Cocaine partnered with Rev. Jackson to alleviate the use of drugs. Rev. Jackson’s famous slogan, “Down with Dope! Up with Hope!”⁴⁴⁰ was a catch phrase for the youth to take a moral responsibility against the dangers of drugs. The National Conference on the Black Family/Community and Crack Cocaine involved 1,200 churches from different denominations and health care professionals.⁴⁴¹ In 2000, the Congress of Black Churches anti-drug and violence campaigns in 37 cities, with almost 2,000 clergy members reaching out to 500,000 people and the Project Anti-Drug Abuse Movement (ADAM) consisted of 100 churches that provided health education on drug abuse.⁴⁴² HIV/AIDS and drug abuse are areas of national involvement for the black church. However, cardiovascular health is another national focus.

prevention initiative." *Journal of the National Medical Association* 97, no. 7 Suppl (2005): 60S, 615.

⁴³⁸ Ibid.

⁴³⁹ Pinn, *The Black Church*, 100.

⁴⁴⁰ Ibid., 96.

⁴⁴¹ Ibid., 97.

⁴⁴² Ibid.

The Progressive National Baptist Convention (PNBC) has partnered with the National Cancer Institute (NCI). PNBC's program through the NCI is called "Body and Soul," which involves 1,100 black churches in 22 states.⁴⁴³ The Body and Soul is a nutrition program with the purpose of cardiovascular disease prevention. The National Baptist Convention USA, Inc. (NBCUSA, Inc.) developed the Health Outreach Prevention Education (HOPE), which I am an active clergy member.

H.O.P.E. is the National Baptist Convention U.S.A. Inc., Congress of Christian Education's Health Outreach and Prevention Education Initiative (H.O.P.E.). This program aims to bring health education, literacy, and programs to black communities as H.O.P.E. take actions that will dramatically improve health and positively impact total well-being. H.O.P.E. Initiative is a member of the national partnership for Action to End Health Disparities and the United States Department of Health & Human Services Office of Minority Health. As apart of the HOPE initiative, I created the Ministry of Health Literacy & Prevention (H.L.P.) at my religious community.

Personal Health Advocacy

The mission of the Ministry of Health Literacy & Prevention (HLP) is to serve our members and surrounding communities through educating about health disparities, providing resources to prevent or stop progressing diseases, supplying biblical principles in nurturing the wholeness of individuals, and advocating for the holistic well-being of humanity. This is fulfilled by developing relationships with local and state health agencies, promoting nutrition and exercise, monthly awareness of a relational disease,

⁴⁴³ DMin, William Booth. "Partnering with the black church: recipe for promoting heart health in the stroke belt." *ABNF Journal* 23, no. 2 (2012), 36.

training health ambassadors, creating relevant programs, events, and activities. HLP's goal is to assist believers to "glorify" God in body, mind and spirit (cf. 1 Corinthians 6:19-20). So we can adequately share the love of Jesus the Christ, as Lord. Such teachings will insure efficient maturation process of all believers as sons and daughters of God by faith (cf. 2 Timothy 2:15).

HLP's goal is to create and sustain a culture of health awareness, literacy, and advocacy in the black church. HLP believes there should not be a separation between spiritual well-being and physical well-being, both should be considered. Our physical and spiritual health will then be evidenced in each of us living as Christian witnesses for the glory of God, the edification of fellow believers and the well-being of souls among relatives, friends, neighborhoods and surrounding communities.

HLP implemented a healthy eating and nutrition initiative to encourage our children and teens to start eating healthy at a young age. We did this by providing a healthy breakfast and snacks every third and fifth Sunday when the children and teens are involved in worship service. At first, the children and teens were a little reluctant but eventually adapted well.

HLP designated specific months throughout the year to focus on health issues prevalent in our local religious community which we give out education materials and have health education talks in worship service called "A Healthy Moment." "A Healthy Moment" is the time of worship service when a health representative of HLP discusses the health topic of the month to the congregation. It is a five minute explanation of the health topic with suggestions for care and prevention. All of the information shared is

backed by credible health organizations. “A Healthy Moment” always ends with the HLP representative encouraging the congregation to see their doctor because the information presented is for education purposes only and each congregant’s personal health is unique.

HLP hosts an annual health fair every August partnering with health organizations including local and state agencies, organize ZUMBA classes every Saturday, and conduct health seminars quarterly. My involvement with the HOPE initiative allowed me to work with the American Heart Association/American Stroke Association as their Multicultural Initiatives Leadership Fellow among black churches.

The beginning of my fellowship started with understanding the American Heart Association/American Stroke Association (AHA/ASA) three year plan. The goal was to reach one million people by 2017, which was done through affecting twenty five to thirty thousand people in specific quarters. In order to reach one million people, the AHA/ASA will use three channels of Housing, Faith Based Organizations, and Strategic Alliances (i.e. other non-profits and libraries). AHA/ASA provided initiatives, tools, and resources through these three channels.

It was imperative to analyze, strategize and utilize resources. Monthly review dates were roughly around the “10th” of every month (i.e. October 10th, November 10th, December 10th, etc.) The reviews examined efficiency regarding the resources and its applicability to the numerous audiences. What was also assessed was the channels and partners’ information, scope of resources, and network. Supportive activity’s goal was to achieve at least 15% of every interaction with audiences.

AHA/ASA initiatives were “C.P.R.” “Check, Change, Control,” “Sodium Pledge,” “My Life Check,” “F.A.S.T.,” and “Heart 360. Hands-Only CPR is CPR without mouth-to-mouth breaths. CPR is recommended for use by people who see a teen or adult suddenly collapse in an “out-of-hospital” setting (such as at home, at work or in a park). It consists of two easy steps: call 9-1-1 (or send someone to do that) and push hard and fast in the center of the chest. Check, Change, Control empowers people to learn about, monitor and manage their blood pressures through a combination of resources. Sodium Pledge helped the AHA/ASA prove to food manufacturers, processors and restaurants that Americans are eager for food with less sodium. My Life Check was designed by the American Heart Association with the goal of improved health by educating the public on how best to live. F.A.S.T. is an easy way to remember the sudden signs of stroke. F.A.S.T. represents face drooping, arm weakness, speech difficulty, and time to call 9-1-1. Heart360 is an easy-to-use tool which helps you understand and track the factors that affect your heart health - including blood pressure, physical activity, cholesterol, glucose, weight and medications.

AHA/ASA’s Founder’s affiliate headquarters is in Robbinsville, New Jersey. It was here I did paper work, picked up and sorted mail, and picked up and mailed materials for events. One of my first events was a house presentation in Newark, New Jersey with different leaders in or related to health and medicine. A chef cooked health appetizers and entrées from the AHA/ASA cook books to emphasize that healthy food can taste just as good or better without fats and salt. I conversed with the attendees explaining the sodium pledge (AHA/ASA’s initiative to lower salt intake) and AHA/ASA “Empower to Serve” ambassador partnership forms.

I was approached about the cook books and other materials displayed and answered questions. I encouraged the attendees to sign the sodium pledge as a personal promise for their longevity and well-being. After my supervisor's lecture, I gave a brief historical account on minority health and went to different individuals giving away free cook books by participants signing an Ambassador form. At the end of the event, I helped clean up and pack up material.

I attended the 2014 Monmouth & Ocean Counties Heart Ball in Long Branch, New Jersey. It was a fun fund-raising event. I donated that night and brought 3 guests joined me in donating to AHA/ASA's cause for research. Two of my guests are emerging clergy in the United Methodist and Episcopal churches. They are very promising in potential AHA/ASA partnerships and other initiatives. I gave both clergy AHA/ASA packets with information about the many AHA/ASA programs. They reported to me that they reviewed the packets and passed the information packet to the senior Pastors of their churches. The senior Pastor in the Methodist church is communication with AHA for a possible partnership. The Episcopal Pastor has not responded, yet. Incorporating health in a Faith based organization can be challenging but I am hopeful that these connections will open partnership opportunities. The other guest is a possible future prospect for internship opportunities with AHA/ASA as a Medical Humanities student at Drew University in Madison, New Jersey.

I had the pleasure of participating at the Sorors of the North Jersey Alumnae Chapter of Delta Sigma Theta Sorority, Inc. Health Fair at the Bethune Cookman Community Center in Jersey City, New Jersey. I brought and set up the display and materials. I discussed the important date of World Stroke Day Info and National Eating

Healthy Day on November 5, 2014. In spite of low attendance, the sodium pledge and Empower to serve sign ups were very solid. I recall some congregants from local churches and a member from a non-profit organization signed an “Empower to Serve” Ambassador form. There were also few people who we sent packages to for World Stroke Day Info and National Eating Healthy Day. There were healthy snacks and fruit, which I helped distribute. Materials and display were packed up and stored for next event.

The New Jersey State Conference of the NAACP Annual State Convention & Health Fair was in Parsippany, New Jersey. Unfortunately, we were put in the back room which negatively affected attendance. However, the few that came I talked to and explained AHA/ASA programs. Specifically, our “F.A.S.T.” and “C.P.R.” handouts. A few people signed the sodium pledge and a couple signed the “Empower to Serve” Ambassador form. An added bonus was reconnecting with my college counselor who worked for the Mental Health Association in New Jersey which opened the door for my alma mater Drew Theological School to create a mental health certification for clergy!

I was the AHA/ASA representative at a Senior Citizen Center in Plainfield, New Jersey. It was a “Go Red: For Women” event. “Go Red: For Women” is a program to prevent heart disease and stroke in women. Specifically, black women are the most susceptible to heart related illnesses. I had the pleasure of educating seniors about our “Go Red” initiative. I shared important information like 1 in 3 women die of heart disease and stroke. African Americans disproportionately suffer higher from heart disease compared to other racial groups and African American women are at the highest risk. I explained the difference between a Heart Attack and Stroke with the technical assistance

of the nurses in the room. I went over the AHA/ASA programs like “Check, Change, Control,” “Sodium Pledge,” “My Life Check,” “F.A.S.T.,” and “Heart 360.” It was a fun and successful event with our seniors being educated about heart health and pledging to lower their salt intake. The “F.A.S.T.” handout and heart information were the hot topics of the night. I heard numerous experiences from the seniors and the information that was said and given was very applicable to them.

I visited the City View Senior Citizen Center in Newark, New Jersey on a monthly basis. I partnered with Linda Barton the Supportive Services Coordinator. The group had 10-15 participants. Linda and I tracked the blood pressure of the seniors and the results are very encouraging. In a six month time frame, all of the seniors’ blood pressures improved! During our gatherings, I have talked and shared with the seniors about all of our programs and distributed educational materials. The seniors’ favorite item was the cook books. I introduced Linda to the “Check, Change, Control” and the “Heart 360” programs to enhance her blood pressure initiative. The entire group signed the “Sodium Pledge” and a handful signed the “Empower to Serve” Ambassador form to connect their local church with AHA/ASA.

My supervisor and I meet with local church representatives at Vonda’s Kitchen in Newark, New Jersey for a breakfast meeting. The meeting was to get acquainted with the local church representatives in Newark and plan future events and initiatives. I listened to the needs of the representatives and took notes on future plans. One of the churches that were represented at the breakfast was Metropolitan Baptist Church. Metropolitan had an event where my supervisor spoke about AHA/ASA programs and I did a brief lecture on Biblical Nutrition and its relation to Health and Wellness. There are foods in the Bible

that are still accessible to us today. My lecture examined foods that were used in biblical times which are useful options for better diet and nutrition in the twenty first Century.

Another church that was a part of the Vonda's breakfast meeting was New Hope Baptist Church. A cooking and health event was held at New Hope where my supervisor talked about AHA/ASA programs. Specifically, she highlighted proper nutrition, "F.A.S.T." education, and the "Sodium Pledge." I aided in answering any questions the audience had by "one on one" conversations, distributed educational materials and healthy eating cook books, encouraged "Sodium Pledge" sign ups, and explained the "F.A.S.T." education initiative through an individual basis. I helped set up, clean up, and pack up materials.

I had the privilege of attending the Building Healthy, Equitable Communities in New Jersey Rutgers NJAES Office of Continuing Professional Education Conference in Edison, New Jersey. Health equity is achieved when every person has the opportunity to attain his or her full health potential. The conference was a great resource and provided me with additional tools and practices to help incorporate health equity into policies and practices to build healthier communities. It was a great learning experience and I connected with great people. It was very applicable to hear from public health professionals and enhanced the quality of my internship participation.

The Living Hope Empowerment Center Church in Trenton, New Jersey had a successful CPR training. The mayor of Trenton and his staff were present and acknowledged AHA/ASA. There were over 50 participants. My primary function was to

help set up materials, chairs, and AHA/ASA display tables. Also, I assisted in clean up and break down.

The 2nd District Conference for the Omega Psi Phi Fraternity, Inc was in Teaneck, New Jersey. There were over 500 in attendance. I helped set up the display in front of the main hall. The other interns and I placed sodium and C.P.R. educational materials on every seat and “Sodium Pledges” on every table for the lunch-in. There were roughly 400-450 individuals that attended the lunch in. The majority of attendees brought the sodium and C.P.R. educational materials home with them and signed the “Sodium Pledge.” A lot of attendees also signed the “Empower to Serve” Ambassador form so fraternity chapters can partner with AHA/ASA. As a thank you for partnering with AHA/ASA the individuals received a cook book. The fraternity members asked numerous questions about “F.A.S.T.,” nutrition, “Check, Change, Control,” “Sodium Pledge,” “My Life Check,” and “Heart 360.” As a result, the conference attendees read and took the “F.A.S.T.,” heart education, and nutrition educational materials.

My work with AHA/ASA is very important. I educated underserved communities about sodium intake, fruit and vegetables consumption, and maintaining healthy blood pressure. I empowered communities through CPR education and stroke awareness. I assisted in establishing Health Literacy and Prevention Initiatives in religious settings and advocated to alleviate health disparities in disadvantage communities.

Black theology’s response to race-based medicine is empowerment and justice. This results in the efficient holistic health of African Americans. Black individuals have the hope and encouragement of mental, physical, and spiritual well-being. Racist

ideologies and theologies used biblical scripture as a weapon but black liberation theology changed harmful interpretation to a means of self-pride. Such hermeneutical change was possible looking at the scripture from black experiences which allowed African Americans to create their own narrative in an unwelcoming society.

In American medicine, black hermeneutics gave African Americans the opportunity to associate biblical illness narratives to their own medical condition for hope to be restored and renewed. Furthermore, black theology and scripture inspired the black church to become self-reliant builders, organizers, administrators, educators, and advocates of black health. Such examples inspired a clergy like me to do what I can to fight against health disparities for those who still are not considered important. Compared to race-based medicine, the black church and black theology are significant agents to mend the fragmented health of African Americans and are much more efficient in solving health issues in minority communities.

CONCLUSION

Race-based medicine is an emerging field in pharmacology, which aims to create a specialty market based on racial groups. The drug BiDil set precedence for this area of medicine targeting African Americans as its first racial group. Immediately, the idea of race as a proxy for disease caused much debate within the medical and pharmaceutical communities. Furthermore, race-based medicine's "starter group" being African Americans caused ethical questions regarding the motive behind race-based medicine because of the treatment of blacks in American medical history. This conclusion will review and summarize the link between race-based medicine and American eugenics, race-based medicine's influence on the perception of the black body, the influence of BiDil's approval on the resurgence of race-based medicine, the black church's response to race-based medicine using black theology, and suggestions for future explorations of race-based medicine.

In chapter one, I mentioned Jean Bapiste de Lamarck an important figure in the foundation of eugenics. Lamarckism the foundation of the eugenics movement was also connected with polygenism and concepts of degeneration. Out of Lamarckism ideology, Charles Robert Darwin formulated concepts about evolution and natural selection in his popular work called *Origin of Species* which produced the field of Social Darwinism. Francis Galton developed the notion of eugenics into a field of science, which evolved into the area of positive and negative eugenics. Under the influences of Karl Pearson, Gregor Mendel, and Walter F.R. Weldon, Charles Davenport brought the practice of negative eugenics into American society and culture.

Davenport shaped the ideology and research paradigm of American eugenics. As a result, the Eugenics Record Office influenced the process of defining and classifying American society. Sociomedical racism became the norm, affecting individuals with Sickle Cell Anemia and Tay Sachs Disease. SCA and TSD were the diseases that spawned the idea of racial diseases. Specifically, SCA researchers created the assumptions that racial groups have different blood types. Such assumptions regarding race-based disease influenced American law and policy. Sterilization, birth control, marriage control, and immigration policies were rooted in the fear and control of race-based disease. The perception that racial groups are innately different formed biological and anatomical theories of difference, which developed into deceitful assertions about racial groups' physiology—especially the observations about African American bodies discussed in chapter two.

Chapter two overviewed the understanding of race and body representation in American history. African Americans were devalued through the misappropriation of their bodies. The dehumanizing denial of black personhood sustained a language and ideology of inferiority. Consequently, pseudo-biological claims compromised the autonomy of black citizens. Physician Samuel Cartwright advanced the understandings of black hardness and black durability. Cartwright's influence expanded the research on race anomalies resulting in slavery, military, and prison race-based experimentation.

Slave experimentation consisted of slave owners and physicians forcing slaves in clinical testing. President Thomas Jefferson and Dr. J. Marion Sims were two prominent figures that used slaves in their research. Military experimentation conducted mustard gas experiments on African American, Hispanic, and Asian soldiers. Operation Big City

piloted a program that spread different type of lung diseases in major cities. The Manhattan Project performed plutonium experiments on African Americans. Prison experimentation was influenced by Jim Crow medicine, which led to harmful tests in the Holmesburg Prison system.

Furthermore, black inmates endured marring experiments like the Sloan-Kettering Institute's cancer tests, the Kilby Draper and McAlester prisons' blood-plasma experiments, and Tulane University psycho-surgery experiments. Ironically, these experiments were conducted at the same time international codes and ethical standards were implemented for clinical trials. By neglecting the process of informed consent, the experiments disregarded African Americans and other racial groups' autonomy, which violated the Nuremberg Code and the Declaration of Helsinki. In response to race-based experimentation, African Americans' developed an oral tradition of fear that resulted in black homeopathy. Black homeopathy became African Americans' medium of clinical justice to participate and be heard in the clinical process. Black homeopathy began the process of African Americans' reconciliation and contribution to medicine.

In chapter three, I examined American discourse of heart disease, FDA's approval of BiDil, and biocapital, medicalization, biomedicalization and genetics' relation to race. The Framingham Heart Study set the precedence of pre-disposition illness testing of heart illness. The pathology of heart disease was understood by racial groups. White people were understood to have heart disease caused by neurasthenia. For most of the twentieth century, most of the cardiology community did not associate African Americans with having heart disease.

The Veterans Administration Cooperative Studies known as Vasodilator Heart Failure Trial (V-HeFT) I and II followed the Framingham Study. The elements of Hydralazine and Isosorbide dinitrate (H/I) were used in the V-HeFT I and II trials. The results of the trial concluded the H/I combination was efficacious in all groups, regardless of race. Cardiologist John Cohn seek to get the H/I combination approved by the FDA. Medco received patent rights to the H/I combination. The FDA denied approval due to unclear data. Cohn constructed the notion that H/I combination had a different effect on African Americans compared to other racial groups.

In Cohn's second attempt of approval, the FDA approved the H/I combination under findings of a race-based "distinction" in clinical trials. The findings were recorded in an article Cohn and Dr. Peter Carson wrote called "Racial Differences in Response to Therapy for Heart Failure: Analysis of the Vasodilator-Heart Failure Trials." The article promoted the African-American Heart Failure Trial (A-HeFT). The results of the trial were convincing enough for the FDA to approve the H/I combination to form the first race-based drug called BiDil.

The FDA had four justifications to approve BiDil. First, data from 3 clinical trials showed dramatic effectiveness of hydralazine hydrochloride and isosorbide dinitrate in black patients and supported a differential effect in black and white patients. Second, not understanding the reasons for the difference in treatment effect by race did not justify withholding the treatment from those who could benefit from it. Third, regulatory and other concerns associated with drug approval for narrow patient populations did not justify withholding BiDil from those who could benefit from it. Fourth, race and other

demographic characteristics have long been important to consider in analysis of trials and as a matter of equity and justice.

The FDA's approval brought up many reservations because the data was misinterpreted and the H/I combination in African Americans produced ambiguous results. A huge reservation of BiDil's approval came from post hoc issues. Post hoc analyses of the two 1980s H/I trials were not exclusively from an African American population but from the general population. The A-HeFT trial did not have another African American population as a control group. Lastly, the black-white ratio was omitted from NitroMed's study.

BiDil's approval raises many concerns because it suspiciously caused more questions than answers. The logic behind approving a drug that had an incomplete clinical process was for financial motives. The FDA approving a drug based on race created a lucrative drug market that targeted racial groups based on illness trends. As a result, race was a form of biocapital.

In relation to BiDil, NitroMed's role in biocapital constructed the notion of race to express an innovative technique for pharmacology and biotechnology. Similar to commercial capitalism, race is speculative in nature based on perception. For example, BiDil stock went up tremendously with its FDA approval but when projections were bleak its stock fell. Financial motives influenced BiDil to have very poor funding and an impulsive clinical process. NitroMed tried to push BiDil into the black community through endorsements of prominent African American health groups like the Association of Black Cardiologists and the National Minority Health Month Foundation (NMHMF). Ultimately, BiDil was not successful because its price caused a financial disconnect for

patient accessibility. BiDil cost more money than its competitors. Since there were alternatives that worked just as well or better than BiDil and cost substantially less, BiDil was not the prime choice for black patients. Most physicians did not prescribe BiDil because of its expensive cost and the racial claims it promotes.

From a legal perspective, the approval of BiDil was not compliant with the FFDC Act and the 1962 Amendments. The efficacy of BiDil for African Americans still was not clear. Also, the approval of BiDil influenced the medicalization & biomedicalization of race. Medicalization is the process when nonmedical issues become interpreted, defined, and treated as medical problems, usually labelled as a certain illness or disorder. In regards to heart illness and health inequity, medicalization is counterproductive because the problem is based on the individual and ignores social factors.

In BiDil approval process, the chair of the FDA Advisory Committee Robert Nissen had poor examples of case studies that led to justifying BiDil's approval. Nissen's erroneous interpretation of case studies connected race with disease. His assertion reified race as a biological truth, which led to the FDA's justification that race was a proxy for disease. Nissen biomedicalized race by approving BiDil as a form of enhancing personalized medicine for the black community.

Biomedicalization used technoscience to produce identity through applying science and technology to our bodies which created identities and labels showed in BiDil. Racial notions imposed assumptions into one's sense of self and redefined new categories of health related identities. BiDil recreated the eugenic stratification of racial bodies as biologically different which draws inaccurate conclusions of disease pathology.

By the mid-twentieth century, UNESCO and other anthropological and sociological organizations confirmed race as ‘myth.’ Carl von Linnaeus and Johann Fredrich Blumenbach created the classification of skin color and racial categories which influenced the United States Office of Management and Budget and United States Patent and Trademark Office (PTO) incorporation of racial categories in American society. The racial categories were used as a means for biological research that supported the appropriation of race and biology in biomedicine. The OMB and PTO racial categories were used in international biobanks. Biobanks used classification which defined ethical choices that brought meaning and identification. The biobanks racial data was based out of the self-identification of individuals which was based on subjectivity. Self-identification does not have legitimate consensus among scientists and geneticists because it is not consistent with findings on the genetic level.

Genome-Wide Association Studies (GWAS) and EIGENSTRAT are technologies used in genetic variation and population. GWAS disease associations require methods for accounting for population differences. EIGENSTRAT is the type of technology that moves from genetic similarity to genetic ancestry to genome geography. Through GWAS and EIGENSTRAT, there was not genetic proof that African Americans are genetically different than other racial groups. Diseases like sickle cell anemia and cystic fibrosis have nothing to do with race but a reality of geography, ancestry and recessive mutations in specific genes. Race-based medicine is not compatible with genetics and cause maleficence because one drug is not adequate to solve an entire racial groups’ illness. Consequently, a race-based drug can cause Adverse Drug Reactions (ADRs) because the genetics of each individual can cause a different reaction from the drug.

Chapter three closes out examining health inequity & discrimination acknowledging race-based medicine cannot be an adequate solution to address these issues. I suggested solutions in the clinical setting by physicians perfecting their cultural competency, empathic communication, and awareness toward minority patients. Also, diet and nutrition is vital in improving health disparities in minority communities. When minority communities have equal access to healthy foods and nutrition education, the health inequity of minority communities can progressively decrease. Other health solutions in the black community are expressed through the black church's advocacy and its use of black theology.

Chapter four discussed the black church's response to race-based medicine, allowing the voice of African Americans to be heard through health advocacy. Black theology was a tool to emphasize autonomy in minority communities by challenging concepts like polygenism that were attributed to scripture. Polygenism, coined by Paracelsus, was the belief humanity descended from two or more ancestral types. Polygenic claims were a result of misinterpretations of the book of Genesis.

In contrast, the Hebrew Scriptures and the New Testament had positive illustrations of black individuals. For example, Moses' Ethiopian wife and Simone of Cyrene were affirmative representations of blackness. Biblical narratives of the gospel of Mark were used as a tool to empower minority communities with their medical challenges. Finally, this chapter explored the past and present black church health advocacy movements and initiatives as substitutes to race-based medicine, and included a reflection on my personal efforts as a black clergyman.

Future Explorations

This dissertation examined the history and relationship between race-based medicine and African Americans. Future research can examine the ways in which race-based medicine skews the perception about black bodies, and how such perceptions affect other social institutions, such as the criminal justice system and the beauty industry. Including other racial groups is significant; each racial group brings its unique experience to American medicine. More work is needed in discovering other racial groups' interaction with race-based medicine. On a global scale, future research can explore if race-based medicine is relevant to homogenous countries. Lastly, in the wake of the recent Ebola and Zika virus outbreaks, analyzing race-based medicine could contribute to understanding immigration debates and laws.

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