

No More Guinea Pigs: Examining African American Distrust of the Medical Community

Thesis/Project

Presented in Partial Fulfillment of the Requirements for the Degree of Master of Arts in the  
Graduate School of The Ohio State University

By

James Johnson, D.Min., BCC

Graduate Program in Bioethics

The Ohio State University

2021

Thesis Project Committee

Dana Howard, PhD

Courtney Thiele, JD, MA

Jordan Brown, PhD

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-Abstract-

In the 21<sup>st</sup> century, we have experienced tremendous growth and innovation in medicine and medical technology. From innovative advancements in drug therapies, assisted reproduction, neuroimaging, chemotherapy, robotic surgeries, and improved skillsets for clinicians, the medical community has made tremendous strides in providing extraordinary services to the community at large. However, the history of medical advancements has not been favorable toward people of color. African Americans have been disproportionately affected by medical abuses and experimentations in regards to medical research. The commodification of black bodies assured the medical community that it had an ample supply of research material. What followed was a history of distrust between African Americans and the medical community that has existed to the present time. The writer argues that getting over the hurdle of distrust will require a re-structuring of the fractured relationship between the medical community and the African American community.

## Dedication

This work is dedicated to my family.

To my dad, James Johnson (deceased) and my mom, Lottie Johnson, thank you for teaching me the value of hard work. It was through your examples that I realized that nothing comes easy but requires dedication and a sincere desire to put your best foot forward to accomplish the task before you.

To my brother, Bryan and my sisters, Jaime, Eva, Erma, and Kim, thank you all for being there for me and encouraging me in my educational endeavors. Although we have not been able to spend a lot of time together, I appreciate you all for your prayers and support.

Finally, I want to thank my wife, Monica, my daughters, Jaslyn and Mariah for putting up with me during those times that I had to take away from our family time to study. For that, I am extremely grateful for your dedication for helping us to achieve this degree.

## Acknowledgements

First, I would like to take this time to thank the administration, faculty, and staff of The Ohio State University for the opportunity to learn and study at such a historic institution of learning. I also would like to thank Courtney Thiele, JD, MA and Ryan Nash, MD, MA for their support and advocacy for allowing me the privilege to be admitted into the Master of Arts in Bioethics program. Especially, Dr. Courtney Thiele who never wavered from being an excellent advisor when I had a thousand questions.

Secondly, I would like to thank Dana Howard, PhD for taking on the responsibility of being my mentor throughout this process. I am extremely grateful for her insights that kept me focused on my passion for this project. Dr. Howard offered her talents and time in order to ensure that this project would be completed in conjunction with the goals and vision of making an impact in my community.

Lastly, I want to thank my thesis project committee, Dana Howard, PhD, Courtney Thiele, JD, MA and Jordan Brown, PhD for taking away from their busy schedules to be a part of this committee and for their feedback and guidance on making this project successful.

## Vita

May 1992.....Covington High School  
May 2010.....B.A. Bible/Theology American Baptist College  
December 2013.....M. Div. Memphis Theological Seminary  
May 2017.....D. Min. Garrett Evangelical Theological Seminary

## Fields of Study

Major Field: Bioethics

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## Chapter 1. Introduction

In the 21<sup>st</sup> century, we have experienced tremendous growth and innovation in medicine and medical technology. From innovative advancements in drug therapies, assisted reproduction, neuroimaging, chemotherapy, robotic surgeries, and improved skillsets for clinicians, the medical community has made tremendous strides in providing extraordinary services to the community at large. Although these medical advancements are changing the lives of millions of people on a daily basis, it requires the altruistic participation of average everyday citizens in research to make this happen. Medical research and the medical community have benefited from those who wanted to improve the wellbeing of society through selfless acts and efforts to advance medical treatments. Sadly, there was a time in American history where altruism was subverted by paternalistic tendencies where the rights of some were diminished and disregarded.

For people of color, the right to choose to participate in medical advancement and research was not a choice but a requirement when one was seen as property. To be seen as property suggests that one has no rights for refusal of what happens to one's body, thus, one becomes expendable to the uses and wiles of the property owner. This aspect of expendability set the stage for people of color to be used as animals rather than humans. Harriet Washington (2006) quotes Dr. Harry Bailey, a neurosurgeon, who spoke openly in a speech at Tulane Medical School in the 1960's about the misuse of people of color in research. Quoting Dr. Bailey, she writes; "[It was] cheaper to use Niggers than cats because they were everywhere and cheaper experimental animals." (Washington, 10) This quote of Dr. Harry Bailey speaks to the sorted history of medical abuse that characterized an acrimonious relationship between the

medical community and the African American community as well as the concept of expendability of people of color. It was this type of disregard for the humanity of African American people that fed and fostered a relationship of distrust that still exists today.

When one feels that one's body is not cared for or valued, there becomes an insurmountable gulf of distrust that cannot be crossed by mere means of a top-down community project or misplaced acts of beneficence. When one distrusts, it is usually tied to an experiential pattern of actions or behaviors which questions the reliability of those who were once entrusted. To overcome the distrust of the medical community that permeates the African American community it requires one to realize the catastrophic effects that institutions and systems have subjected African Americans to and the reformulation of what it means for African Americans to be human and treated as such. In this project, I argue that distrust can be shifted to trust by examining past, present, and future behaviors. I believe doing an honest assessment of African American distrust of the medical community and offering a new paradigm for engagement can be crucial in re-establishing trust.

I seek to do this by examining the historical perspective which led to people of African descent to be viewed as less than human and the catastrophic effects it has had on them. Additionally, I seek to contextualize this historical perspective and offer a paradigm shift where the demons of the past can be confronted and a new concept of what it means to have value and a voice can be inculcated into a practical aspect of a trusting relationship. I will attempt to do this through the lens of narrative ethics where the story of African Americans' past affect how they view trust and distrust of the medical community. I believe a "top-down" approach of some

organizations to engage the community does not go far enough to address distrust in African American communities.

Lastly, I want to develop a plan of action where the voices of the African American community will take the lead in bridging the gap between the African American community and the medical community where both voices are incorporated into a dialogical and developmental project. This will be done using the evangelistic principles found in Glen Martin and Gary McIntosh's book, *Finding Them and Keeping Them*. The principles found in this book show how one engages a community and allows the community the opportunity to build a trusting relationship with future stakeholders. By doing this project, the expectation is to offer a paradigm that could be used in various settings in an effort to dissolve the distrust that is so often present within African American communities. The goal is to give the African American community the ability and autonomy to be actively a part of the care that can be beneficial for them through medicine and medical research.

## Chapter 2. Historical Perspective of Distrust: How Did We Get Here?

Throughout the history of the United States of America, the country has prided herself on being a place of democracy, freedom, and opportunity. Her forefathers sought to establish a more perfect union where every person would be considered equal. By establishing a Constitution and Bill of Rights, the United States of America assured every American the right to life, liberty and the pursuit of happiness. It would become evidently clear that this declaration of independence would soon be a declaration of interdependence where people of color would not be considered people but property. Institutions and systems would be established to ensure the subservience of people of color to these institutions and systems. The institutions and systems that would play a major part in the subservience of people of color was local and state governmental establishments, the medical community and slavery. This triadic homogenous relationship of government, medicine, and slavery played a vital part in the degradation and defamation of people of color.

From the government sanctioning of the buying and selling of people of color as slaves to the disregarding of them as research subjects in medical experimentation, people of color have not been able to fully embrace the principles and practices of a country that prides herself on life, liberty, the pursuit of happiness and the American dream. In fact, the illusion of personhood for people of color created an acrimonious relationship where distrust and disenfranchisement overshadowed the promise of the equality of all humanity. Starched in her history is a dichotomy of personhood and property that reflects the lived experience of people of color, particularly, those of African descent.

### People or Property?

What does it mean to be a person? At what point does one gain personhood? These are just a couple of questions that must be answered in order to assess why the mistreatment of black bodies. In bioethics, there are notable definitions for what being a “person” means. H. Tristram Engelhardt, Jr. (1996) would argue that a “person” is different from a human. Engelhardt (1996) argues; “What distinguishes a person is their capacity to be self-conscious, rational, and concerned with worthiness of blame and praise.” (Engelhardt, 138) He goes further; “On the other hand, not all humans are persons. Not all humans are self-conscious, rational, and able to conceive of the possibility of blaming and praising. Fetuses, infants, the profoundly mentally retarded, and the hopelessly comatose provide examples of human nonpersons.” (Engelhardt, 138-139) Engelhardt’s argument of personhood hinges on one’s mental capacity to be able to self-consciously rationalize right from wrong and/or blame or praise. So, does that mean that “human nonpersons” do not deserve the same respect? On the contrary, Engelhardt makes the point that for “human nonpersons”, fetuses, infants, the profoundly mentally retarded, and others may not be afforded the status of a person in the strict sense; but, they can be afforded the status of a person in the social sense. He argues:

Since this sense of person cannot be justified in terms of the basic grammar of morality (i.e., because such entities do not have intrinsic moral standing through being moral agents), one will need rather to justify a social sense of person in terms of the usefulness of the practice of treating certain entities as if they were persons. If such a practice can be justified, one will have, in addition to a strict sense of persons as moral agents, a social sense of persons justified in terms of various utilitarian and other consequentialist considerations. (Engelhardt, 147)

Therefore, Engelhardt’s stance does not disregard the protection of nonpersons rather offers significant considerations for those who seek to justify caring for nonpersons through supporting virtues such as sympathy and caring, protections against uncertainties and various

vicissitudes of competence and incompetence, and the practice of child-rearing. (Engelhardt, 147-148)

Conversely, Beauchamp and Childress (2013) notes the fluidity of such definitions of persons or personhood. They argue; “What counts as a person seems to expand or contract as theorists construct their theories so that precisely the entities for which they advocate will be judged to be persons and other entities will not.” (Beauchamp and Childress, 68) For Beauchamp and Childress, using restricted language about persons and personhood leaves blurred lines about the respectability of various entities. What Beauchamp and Childress highlight is the hermeneutical lens through which one can assess what one should or should not respect based on acceptable parameters set by scientific inquiry or societal norms. The hermeneutics of personhood played a big part in how African American people were treated. To be a person means that one is respected, one’s rights are protected, and one’s wellbeing is placed at the forefront of care. It means to adhere to the principles of autonomy, beneficence, nonmaleficence, and justice as outlined by Beauchamp and Childress.

For African Americans, it is more than abstract principles to be applied but a narrative; a narrative of a human living document whose life, lineage, and legacy are engulfed into a story of struggle and survival. Without the narrative of African Americans’ understanding of personhood in relation to historic treatment as property, African Americans are no more than lifeless, expendable tissue. The narrative and narrator are important to valuing African Americans as persons. McCarthy (2003) says of narrative ethics; “On this view, when ethically challenging situations arise, it is not the medical chart, the proposed treatment, and the ethical rules that might govern that treatment which are at the center of moral interest. Rather, it is the whole

journey of an individual's life as they conceive it themselves that is privileged.” (McCarthy, 67)

Unfortunately, this designation as a person, caring for them, or understanding their story was not afforded to people of African descent because of their potential for profit as property. The enslavement of people of color, particularly people of African descent, in America became an opportunity for financial gain.

What was once indentured servitude, working off of one's debt through service regardless of race, was now seen as an opportunity to enslave people based on the color of their skin rather than accumulated debt. In Virginia around 1640, the separation of servants based on race was becoming the norm. Franklin and Moss (1994) write; “when three runaway servants, two white and one black, were recaptured, the court ordered the white servants to serve their master one additional year. The black servant, however, was ordered “to serve his said master or his assigns for the time of his natural life here or elsewhere.” (Franklin and Moss, 57) Franklin and Moss accentuate how people of color were criminalized and degraded on the basis of a misguided hermeneutic of who should and who should not be considered a person. What was once indentured servitude was now the enslavement of black bodies for profit and gain. The move from indentured servant to property and profit placed African Americans in a precarious situation. They would no longer be seen as people but things, animals, or an “other” to be used for the capitalistic desires of her or his master. The enslavement of black bodies became a lucrative business where many wanted to be a part.

Since blacks were looked upon as having a lesser intellect, the slave master became, by way of ownership of his newly acquired stock of slaves, in essence, the surrogate decision-maker for his slaves. Washington (2006) speaks to this dynamic of reasoning when assessing Samuel A.

Cartwright, M.D. claim of black inferiority. She writes; “Cartwright suggested that blacks’ physical and mental defects made it impossible for them to survive without white supervision and care, alleging that the cranium of blacks was 10 percent smaller than that of whites, preventing full development of the brain and causing a stunting of the intellect.” (Washington, 36) It was this pseudo-paternalistic aspect of slave masters and those who enabled them to assert the inferiority and “otherness” of African American people in order to exercise control over them. To put someone in the realm of something other than human seems to justify barbaric and racist actions and attitudes toward her or him, thus, to be herded as cattle rather than valued as human beings.

Douglas A. Blackmon (2008) writes about a man named J.M. Brown during the 1850’s that considered himself “not a planter but a Negro raiser,” growing no cotton on his plantation but breeding slaves on his farm specifically for sale on the open market.” (Blackmon, 43) Blackmon (2008) continues; “slaves were like assets to be expended like mules and equipment.” (Blackmon, 44) “In an economic formula in which there was no pretense of paternalistic protection for slaves, the overseers drove them mercilessly.” Quoting planter James H. Ruffin in 1833; “The Negroes die off every few years, though it is said that in time each hand also makes enough to buy two more in his place.” (Blackmon, 45) The total disregard for the health and wellbeing of African Americans during this colonial period shows that people of color were expendable property rather than people to be valued. The precedent set during slavery set up the misuse of black bodies as “guinea pigs” in medical research to be discarded as trash and replaced without regard for their personhood. African Americans could not trust that their white “benefactors” were acting in their best interests. In fact, their racist tendencies to misuse and mistreat them based on the color of their skin showed forth their true interests, themselves.

The acts of beneficence and nonmaleficence for African Americans were only applicable when it benefitted those who would profit from their labor. The care being offered to slaves was for the sole purpose of more productivity and profit. Thus, a suspicion of the slave owner's intentions permeated an already contentious relationship. Care that seemed beneficial on the surface would be met with skepticism because of the binary actions of the slave owner to beat and whip on one hand and offer medical treatment on the other. How can one trust when one's experiences say otherwise? To trust means to entrust one with something of value. When trust has been violated, a gulf or chasm exist which sometimes cannot be narrowed without a re-evaluation of what has been broken or violated. Therefore, when one cannot trust the actions of others, are there any safeguards to assure those who have been violated that equitable justice is available? Will the legal system be the wall of defense for the marginalized and mistreatment of people of African descent?

### Legalization of People as Property

The legal system played an essential part in continuing the de-valuing of black bodies and protecting property interests. One would assume that one who is faced with mistreatment and maleficent behavior that the laws of the land would protect them. In the case of the legal system, this would prove to be a mere fallacy for African Americans. With the mistreatment of African Americans by their slave masters, the legal system of local, state, and national governments reinforced and did not rebuke the maleficent behavior of slave owners. In fact, when one examines the U.S. Const. art. IV, § 2, it seems to endorse indentured servitude or slavery by stating that a person escaping from one state to another does not free him from his labor or service. (U.S. Const. art. IV, § 2) In the case of *Dred Scott v. Sandford*, the Supreme Court ruled in favor of Sandford by an 7-2 decision upholding U.S Const. art IV, § 2 that Scott did not have

the rights of a citizen because he was a slave, thus, property and could not seek his freedom because of jurisdictional laws outlined in the constitution. ([www.oyez.org/cases/1850-1900](http://www.oyez.org/cases/1850-1900)) What the Supreme Court decision ultimately did in Dred Scott v. Sanford was reinforce the racist, systemic relationship between law and slavery which violated the autonomy, beneficence, nonmaleficence, and justice of people of color.

In Virginia, new legislation in the nineteenth century would prove to be just as strenuous and racist. These laws were put in place to intimidate and suppress the movement to freedom by slaves. They extended from the freedom of black people to religious practices. For example, Emily West cites Black Laws in Virginia to offer insight after the insurrection led by Nat Turner. West (2012) cites; “No slave, free negro or mulatto shall preach, or hold any meeting for religious purposes either day or night.” Up to “thirty-nine lashes” faced those caught breaking this law.” (West, 33) West continues regarding the emancipation laws of slaves around the age of twenty-one. West explains; “New legislation in 1848 decreed that any free black would “forfeit his right to freedom” and be sold as a slave if he remained in Virginia for more than one year following emancipation after the age of twenty-one.” (West, 34) These laws were used to exercise control over people that was considered property and having no rights challenge or rebuke the systemic racist practices of the law or slavery. In order to exercise this dominance, the lawmakers and slave owners were intertwined in a trusting relationship where the interests of both were being protected. The subsequent rights of people of color were nonexistent because “property” or “things” did not have claims to legislative freedoms or rights.

After the 13<sup>th</sup> amendment was passed on January 31<sup>st</sup> 1865, the hope was that people of color would somehow be excluded from the oppressive and racist laws that had governed them

for so long. However, as Margaret A. Burnham points out, that would not be the case. Burnham (1996) says; “The postwar period signaled the aggressive use of criminal law to constrict black autonomy in family life, civic affairs, and the labor market.” (Burnham, 434) Criminal law statutes would be used to enact apprenticeship laws. Apprenticeship laws were laws used to justify seeking work for a person, in this case people of color who were newly emancipated, learning a craft or trade. After the Civil War, blacks, particularly in the south, could not find work and were not able to provide for their families. As a result, apprenticeship laws were used to indenture black children without regard to the ability or care capacities of parents whose rights as parents were disregarded. (Burnham, 436) The consistent and flagrant abuse of power by slave owners and legislation to amass people of color as property only heightened the distrust of African Americans regarding the institutions and systems that sought to perpetuate a veil of inferiority over people of color.

African Americans, in the south, became keenly aware of the tactics that were being used to continue an outlawed system of slavery. Distrust of the legal system and slave owners had its roots in the non-paternalistic tendencies which tried to re-invent an old system of brutality and control. As someone who has lived in the south all of my life, the remnants of my ancestors’ voices still ring today as loudly as in the nineteenth century. Stories are still being told of how African Americans were treated and how as an African American male that I have to be careful about where I go and what I am doing in the public square. This distrust of systems has generational implications for the disconnect between African Americans and the institutions and systems of today. If they could not trust that slave owners were looking out for best interests and the legal system was not there to protect and serve African Americans as rightful citizens, could

they trust the medical institutions that would offer health care to them during their time of illness and vulnerability?

### In The Name of Medicine

So far, we have examined how slavery and the legal institutions have played a part in upholding African American distrust of institutions and systems by degrading them to no more than “property” or “things” to be used and discarded. Medicine’s role in the history of African American distrust is equally as alarming and culpable. In medicine’s signature tenant, the Hippocratic Oath, “a new physician is required to swear upon a number of healing gods that he/she will uphold a number of professional ethical standards, to have an allegiance to her/his teacher, and to bring no harm to her/his patients.” (retrieved from [www.nlm.nih.gov/hmd/greek/greek\\_oath](http://www.nlm.nih.gov/hmd/greek/greek_oath)) The key principles of the Hippocratic Oath are beneficence, nonmaleficence, and confidentiality. The obligation was to ensure that everything that was being done in the name of medicine was to benefit and not harm the person being cared for. Somewhere between the time of Hippocrates and the burgeoning slave trade in America, the principles of beneficence, nonmaleficence, and confidentiality were lost; unless, those who the physician was charged to treat were actually not a people at all, but, exploited, experimental, research animals. What happened between the medical edicts of Hippocrates and the slave trade in America where people of color would be used as “guinea pigs” rather than suffering patients in need of medical treatment?

Washington (2006) helps one to understand this move from beneficence care to maleficent behavior and treatment towards people of color. Washington says; “Slaves’ immune systems were unfamiliar with, or naïve to, microbes that caused various pneumonias and

tuberculosis. Parasitic infections and abysmal nutrition also undermined blacks' immunological rigor." (Washington, 29) The compromised state of African American health could be attributed to the horrible conditions in which they lived. Often living in small shacks that were airy structures which made them susceptible to the elements around them, different illnesses befell them in a way that whites did not experience. Hearing stories from elderly family members about outdoor toilets, homes without insulation, and floors one could see through were commonplace in African American communities during the nineteenth and early twentieth centuries. In fact, my mother would often muse about seeing the chickens under the house and how being one of my grandmother's twenty-one children, of which some died at birth, she had a responsibility to help take care of her siblings. The conditions they endured and the illnesses they contracted were due in part to a system that believed in the inferiority and exploitation of black bodies.

Washington (2006) speaks to the medical atrocities that fell upon African Americans during the eighteenth and early nineteenth centuries. Washington writes:

Physicians' memoirs, medical journals, and planters' records all reveal that enslaved black Americans bore the worst abuses of these crudely empirical practices, which countenanced a hazardous degree of ad hoc experimentation in medications, dosages, and even spontaneous surgical experiments in daily practice among slaves. Physicians were active participants in the exploitation of African American bodies. The records reveal that slaves were both medically neglected and abused because they were powerless and legally invisible; the courts were almost completely uninterested in the safety and health rights of the enslaved. (Washington, 29-30)

The complacency and complicity of what has been coined in this project as a triadic relationship between slavery, local, state, and national laws, and medicine show forth the disregard for the health and wellbeing of people of color. This triadic relationship left people of color with an obscure sense of who could be trusted to act in their best interests. The fear of medicine and physicians manifested itself when physicians did little to stop the abuse perpetrated by slave

owners and often agreed with the tactics. Washington states; “Owners and physicians also blurred the therapeutic line by referring jocularly to whipping as “medicine” for malingering slaves.” (Washington, 31) This motif of blacks being “lazy” and black women, in particular, as being “welfare queens” finds its origins in a racist past of a triadic systemic relationship that still permeates laws and institutional structures of our society today.

When one looks at the mistreatment and exploitation of black bodies that fostered distrust, one needs to look no further than documented occurrences where black bodies were exploited in the name of medicine. There was and, I believe, still exists a racialization of medicine that hold to the remnants of past practices. Hoberman (2012) argues:

Colonial medical science thus combined intellectual curiosity with ambition to control the natives and to change them in ways that were advantageous to Europeans. Combining intellectual curiosity with racial anthropology produced the phenomenon we may call racialization, the imposing of a variety of racial meanings onto the anatomical, physiological, and psychological traits. Racialization floods the body and everyday life with racial meaning by generating folkloric interpretations of apparent racial traits and oppositions what blacks eat, how well they sleep, how fast they run, how musical they are, how often they have sex, how they age, how their children gestate and grow, and so forth. (Hoberman, 69)

Hoberman’s argument about racialization supports and sustains how African Americans have been characterized in the past which endorsed experimentation and mistreatment of black bodies. Two words in Hoberman’s assessment should catch one’s attention. Those words are curiosity and control. It was the curiosity about the make-up of black bodies which allowed them to endure certain conditions which was intriguing to their white slave owners. Their ability to handle the rigors of an everyday workload in extreme heat as well as cultural and religious practices that reinforced a sense of identity threatened the assumed superiority of the white slave owner. In order to control the slaves, false narratives about physiological and psychological

attributes of African Americans were used to show forth inferiority and control. The medical community's part in this perpetuation of a false narrative can be seen in various examples throughout its history. Savitt (2005) explains; "Some politically minded physicians explained the southern position on slavery in publications to show that slavery was humane and economically viable because blacks had immunity to certain diseases that devastated whites." (Savitt, 14) This narrative of physiological differences gave credence and license to capitalistic ventures at the expense of a people whose humanity and voice were not heard or valued.

What Savitt helps one to understand is that slavery was not an isolated situation of capitalistic slave owners alone; rather, it was an intertwining of institutions and systems at play that afforded such misguided assertions about black people and black health. Conversely, the same conditions and diseases that were thought to give black people immunity were also used as justification for the inferiority of black people. Savitt (2005) says; "White observers seized on the physical differences to illustrate the inferiority of blacks to whites, to rationalize the use of black people as slaves, to justify subjecting black slaves (rather than white laborers) to harsh working conditions in extreme dampness and heat in malaria regions, and to prove to their critics that they took the special medical weaknesses of blacks into account when providing care for their human chattel." (Savitt, 15) This motif of "inferiority" of black people to white people gave the slave owners and medical community, in their minds, scientific justification and validation for experimenting on black people in the name of paternalism and medical research.

Unfortunately, when people face inequality and mistreatment, the narrative about them can become the narrative that shapes them. The loss of autonomy and sense of self can cause the oppressed to feel as if what they were experiencing was a part of a natural order where they had

to submit themselves to the control of the slave owners and physicians. The emotional blackmail or psychological branding of slaves as property set the narrative that slaves were unable to function or care for themselves without the assistance of slave owners and their physicians. However; the fiduciary responsibility of physicians, in particular, to slaves should have hinged on a caring relationship rather than for financial or selfish gain. Kenny (2010) affirms the interests of the slave patient was often manipulated for the professional development of the physician. Kenny (2010) states:

However, most slave hospitals in the American South, especially those with commercial and experimental roles, did not operate simply to provide patients with comfort, warmth, and light; rather they functioned as mechanisms for the maintenance, restoration, insurance, and enhancement of commercial value for the objectified chattel they housed, as well as to provide spaces in which southern doctors could develop their knowledge, raise their profile, and sharpen their professional skills. (Kenny, 5)

When the interests and relationship between slave owners and physicians seemed intertwined, black people began to prefer self-treatment and herbal remedies because of the distrust they had for the medical community. (Savitt, 15) Nonetheless, there were documented examples of how black bodies were used as “guinea pigs” for capitalistic gain and scientific discovery. One notable example of medical experimentation on African Americans was conducted by the hands of Dr. James Marion Sims. Dr. Sims is a classic example of the relationship between slavery and medicine because he shared an interest in buying and selling slaves as well as using them for medical experimentation. (Washington, 54-55) One notable incidence was a procedure that Dr. Sims conducted on a seventeen-year old slave girl by the name of Anarcha who encountered problems during the delivery of her child. Anarcha developed what is known as a vesicovaginal fistula. “Vesicovaginal fistula is an abnormal opening between

the bladder and vagina that results in continuous and unremitting urinary incontinence.”

(Stamatakis et al., 2014, 131)

Between 1845 to 1849, Dr. Sims, with cooperation and submission of Anarcha and several other slave women, performed up to thirty operations for vesicovaginal fistula. In 1849, Sims’ perfected his procedure and the women were ultimately healed. (Savitt, 1982, 345) Dr. W. Montague Cobb (1951) pushes against the assertion that Anarcha and others involved in these operations were “guinea pigs”. Cobb writes; “To refer to Anarcha, and the five other vesicovaginal patients whom Sims treated with her, as guinea pigs, would be grossly unfair, as Sims continued to treat and provide for these girls at his own expense for three years in the little hospital in his yard, against enormous pressures from his family, the profession and the public.” (Cobb, 148)

Cobb believed because of their condition which caused severe pain and discomfort Sims did a humanitarian service for caring for them. However, what is missed in Cobb’s assessment is that these women suffered the same condition as white women but were sought out by Sims for the expressed purpose of experimentation. Relating back to the motif that blacks tolerated pain better than whites Sims intentionally sought to use black women, in particular, to perfect his procedure. Seeing that Sims had a dual interest, in that, he was a physician and slave owner, the exploitation and experimentation of these black women preyed on their vulnerabilities which was not built on trust but as being Sims’ property. To assert that Sims’ success in this procedure was built on consent rather than control would be absurd. For slaves who did not have a voice in matters pertaining to their health or wellbeing could not refuse even if they disagreed or

distrusted. Therefore, their autonomous consent was replaced with a seemingly paternalistic beneficence that actually benefitted Sims academically and professionally.

Medical experimentation of the past did not stop with Anarcha. Sam, a twenty-six-year-old slave who suffered from an osteo-sarcoma of his lower jaw for at least five years, was seen by Dr. Sims because efforts by other physicians were fruitless because Sam refused to submit to being cut. (Kenny, 19) Against Sam's will, he is strapped down to a chair and Sims performs the procedure and even used a chain-saw to remove the mass from Sam's jaw. (Kenny, 20-21) The objectifying manner in which slaves were used for medical research and treatment added to an already acrimonious relationship of distrust with slave owners and the medical community. As Kenny notes; "As the physician's paying client, the slave owner's interests were paramount, whereas the slave was effectively rendered voiceless and powerless." (Citing Sims, Kenny, 22) Sam becomes no more than an object, a piece of material that can be used at Dr. Sims' disposal.

The continual perpetuation of African American bodies as "guinea pigs" can also be seen in the thriving slave markets in New Orleans. Two prominent examples of the abuse, experimentation, and exploitation of black bodies in New Orleans were that of Hotel Dieu and Touro Infirmary. These hospitals became an attractive venue for slave owners who wanted to get the most out of their investment in the slave trade as well as practicing physicians.

"Negro infirmaries" were adapted in the antebellum South helps to clarify both the relationship between orthodox medicine and slavery and also underscores the extent to which southern physicians absorbed and reinforced slaveholding values. Indeed, many experimental and commercial southern hospitals played important roles in restoring, preserving, insuring, and enhancing the value of slave property, key functions in the business of buying and selling black bodies, and perhaps none more so than hospitals located in the domestic slave trade's foremost market- New Orleans. (Kenny, 25)

This collaboration between the medical community and slave owners furthered the gulf of distrust amongst the slaves. The aspect of acting in a paternalistic manner for the best interests of black people was absent although it was falsely portrayed to slaves. If slaves could not trust their owners or the medical community, fear replaced trust and suspicion of white people and the medical community would become the narrative passed down to subsequent generations. To further this distrust during the height of slavery, black people were not even respected once they died. Various accounts of grave robbing show forth that black bodies were still valuable to slave owners and the medical community for continual medical research even after death. Savitt (1982) says; “Black fear of medical schools and dissection inevitably carried over into the postbellum period, when whites, as a means of maintaining control over freedmen, reinforced the idea of “night doctors” who stole, killed, and then dissected blacks.” (Savitt, 340)

The use of black bodies for medical experimentation provided financial resources for slave owners and ample research material for physicians and the medical community. The absence of respect for black bodies formulated a belief in the African American community that medicine could not be trusted. The catastrophic effects of the actions of physicians and the medical community when it came to postmortem dissection still has lasting ramifications. There remains a reluctance in the African American community regarding organ donation due to the belief that medical treatment would be withheld in order to harvest their organs.

It goes without saying that history has shown through various examples that African American distrust of the medical community is well founded. Whether it was the slave trade in North America, medical experimentations on African Americans in the antebellum south, forced sterilizations in the south, the continual use of the HeLa cells of Henrietta Lacks by John

Hopkins University, human experiments at Holmesburg Prison or the Tuskegee Syphilis Experiment, what is evident is the disregard for the autonomy and personhood of African Americans led to an increasingly intense distrust of slave owners, the legal system, and the medical community. This triadic relationship of exploitation of African Americans had and has lasting effects that still permeate how African Americans access and utilize medical resources. Healthcare disparities was a result of institutions and systems that used racial, physiological, and psychological dimensions as evidence for the inferiority of African Americans. These disparities in healthcare were enforced through institutional barriers that limited access to life altering and life-sustaining treatments to African Americans.

Nonetheless, with changing attitudes about the use of human subjects in research, laws governing the use of human research subjects offered protections for persons being asked to participate in research studies. These protections extended as well to African Americans who were once isolated by the color of their skin but were now afforded the principles of autonomy, beneficence, nonmaleficence, and justice in the treatment they received. With the Nuremberg Code of 1947, the Declaration of Helsinki which was written by the World Medical Association, and the introduction of Bioethics in the 1970's, ethical codes were being put in place to assure that the mistreatment of human subjects would not happen in the future. The co-conspirator nature of slavery and medicine to profit on the backs of oppressed people of color was now being regulated under the very legal code that once undergirded the use of African Americans as unwilling research subjects.

Establishing boundaries of ethical conduct gave African Americans an opportunity to gain a sense of independency where medical decisions could be made on their own terms without

the coercion or paternalistic oversight of an overseer. Informed consent assured African Americans that medical information would be given in laymen terms and explained before any medical procedure would be performed. Although these protections and provisions were put in place, African American iatrophobia (fear of the healer) persisted because the relics of the past still reminded them that their best interests were not usually at the forefront of medicine and society. At present, there have been organizations that seek to change the perception of African Americans when it comes to the medical community by offering programs that focus on African American healthcare issues. The issue at hand is most organizational approaches operate from a top-down model of engagement with the African American community and does not engage the real life experiences of those communities. The question becomes does the top down model of community engagement fully address the past transgressions of a complicit medical community which profited from a triadic relationship that fostered an atmosphere of distrust?

### Chapter 3. The Need for Community Connect

In recent years, there has been efforts to address the inequities of African American healthcare in an effort to reconcile the past transgressions of the medical community. Although strides have been made, in the rural south remnants of a racist past reminds its inhabitants that there is still a long way to go. In some rural communities there are still courthouses where slaves would have been auctioned off, statues of racist confederate soldiers extenuate these courthouse lawns, and inadequate healthcare that does not meet the needs of the community. As an African American Christian from the rural south, what is often overlooked in bioethics and medicine is the connection between racism, religion, and medicine. The apprehension and distrust that exists in the rural south come as a result of the past homogeneity of racism, religion, and medicine. This plays a major part in how medical treatment is received and implemented in African American communities in the rural south. Therefore, the black church becomes an important factor in making sure that trust can be facilitated between the African American community and the medical community.

Being from the rural south in a small town of slightly over ten thousand people, there has not been the kind of effort needed to address the past transgressions of slavery as well as the continuing faltering understanding of the healthcare needs of African Americans, in particular. In small rural towns, healthcare is scarce and hospitals, for some, are non-existent. In my town, Brownsville, Tennessee, the closest hospital system is about thirty miles east in Jackson, Tennessee or forty-five minutes west in Memphis, Tennessee. Haywood Park Community Hospital closed in July 2014 due in part to Gov. Bill Haslam's refusal to expand Medicaid in the

state. ([www.jacksonsun.com](http://www.jacksonsun.com)) It is estimated that the patient to primary care physician ratio in Haywood County is 3004 to 1. ([www.data.usa.io](http://www.data.usa.io))

Within the rural context of Haywood County, in which I live, there has been little effort to replace the local hospital that provided care to a county which consists of over 10,000 people in the city of Brownsville and nearly 18,000 in the whole county. Of those roughly 18,000 people, sixty-five percent are African American. The closing of the local hospital not only affected the healthcare in the area but also the potential for economic growth. One hundred million dollars was invested in an industrial park in Haywood County but it is now no more than a grassy hillside because without adequate accommodations businesses refuse to bring their businesses to Haywood County. Consequently, fewer high paying jobs means fewer opportunities for quality healthcare. Connell et al. (2019) has noted; “The South has a higher rate of poverty than the other regions, as well as poorer status for several commonly tracked health outcomes, including obesity, diabetes, and infant mortality, and for health insurance coverage.” (Connell et al., 636)

Many felt the move on behalf of the governor was motivated by an agenda to use the Affordable Care Act, initiated by President Obama, as means for not expanding Medicaid in the rural communities which are usually heavily minority communities. Public health facilities which usually serves underserved communities has experienced a continual decline in funding and support. Byrd and Clayton (2001) suggests:

Thus, the growing black underclass will continue to be served by the inferior public health subsystem and ignored by private sector medicine. The public institutional infrastructure, though serving a laudable purpose, has not adequately met the health needs of black and poor populations for more than three centuries-with resultant and understandable poor health outcomes. (Byrd and Clayton, 224-225)

The inadequate ability of public health systems to meet the various needs of African American communities shows that the dialogue between the African American community and the medical community continues to be a dialogue of paternalism rather than what is most needed by the community they serve. The “inferior public health subsystem” as outlined by Byrd and Clayton (2001) speaks to a dynamic experienced by many African Americans in rural communities. Distrust, particularly among the African American community in the rural south, stems from past experiences with its history of racism/slavery, diminished health care access, and lack of local and state governmental involvement in the overall health needs of African Americans. Structural barriers play a tremendous part in the continuation of distrust among African Americans.

For Haywood County, poverty is a key factor in the health and wellbeing of its citizens. In Haywood County, the median income is around \$31, 900 a year with the lowest income bracket being around \$10,000. ([www.datausa.io](http://www.datausa.io)) Manufacturing is one of the major income drivers in our county. In recent years, there has been a reduction in manufacturing jobs due to companies moving out of town or completely shutting down. In the manufacturing industry in Haywood County, roughly about 70 to 80 percent of the workers are African American. When there is a reduction in job access, then, there is also a reduction in access to healthcare. Another barrier is when one lives in a rural community, access to receive healthcare becomes an issue when there is no public transportation to transport someone to a doctor’s appointment. In their study, Connell et al. (2019) found that transportation whether public or private was a barrier to receiving the care that the participants in that study needed. (Connell et al., 638) It is extremely troubling when the gulf widens between recipients and resources based on political agendas or discriminatory practices which affect the wellbeing of average citizens.

One of the most important barriers to healthcare in rural communities, especially African American communities, was the issue of trust or distrust of the medical community. With a patient to physician ratio of 3004 to 1, it becomes difficult to build the type of trusting relationship required to affect a proper health outcome. “Medical distrust and discrimination/racism appear in many studies of low-income, ethnic minority populations as interpersonal barriers to seeking health care.” (Connell et al., 637) In rural communities, the remnants of a racist past adds to an already overarching issue of health disparities. With this type of patient to physician ratio, the assumption may be that I am not being seen because of the color of my skin. Hammond (2010) says; “Perceived racism in healthcare has been cited as an important determinant of African Americans’ trust in medical organizations and willingness to utilize services.” (Hammond, 92) When people of color feel like they are being discriminated against, it fuels past feelings of distrust and shuts down further communication or engagement with the medical community.

In 2014, when Haywood Park Community Hospital closed, there was a scramble to try to figure out the next steps forward. The citizens of our small town and the newly elected mayor, Bill Rawls, who was the town’s first African American mayor, felt political and racial motivations were the cause of the hospital closure. Skepticism about the motivations of Governor Bill Haslam and his administration led to an already distrustful environment where African Americans felt marginalized based on the level of care they received and now, the complete closure to the limited access of healthcare they did have. What was left as far as healthcare was the local health department and a few physicians and nurse practitioners. With a stressed healthcare environment, those entrusted to care for the community found themselves bombarded with patients with complex medical histories. What can happen is implicit biases heighten due to

the population one serves and basic assumptions about the person before the physician or nurse practitioner can overshadow what is actually presented.

For example, when my daughter was in the fourth grade, she experienced frequent pain in her abdomen which would keep her up at night. She complained of excruciating pain in her lower abdomen which affected her sleep as well as her school work. We consulted the local physician who seemed to be the most compassionate when it came to children and he diagnosed her with a bladder or urinary infection. Without any bloodwork or other diagnostic testing, she was given medication for a urinary infection. This issue persisted for almost two years and we tried physicians at a well-known children's hospital in Memphis that associated her pain with dairy products, made return visits to our local physician who continuously misdiagnosed her, and finally, one of my wife's co-workers, who was a white woman, explained that her daughter had some of the same symptoms our daughter had and suggested an outpatient clinic in nearby Jackson, Tennessee. What was diagnosed as a urinary infection in Brownsville and possibly discomfort related to dairy products in Memphis was actually gastroparesis, which deals with a slow movement of contents through one's digestive system. What was disheartening about this situation was routine testing could have identified her problem but assumptions were made and proper care was not offered for my daughter's illness. What resulted from this interaction with our local physician and the physicians at the children's hospital was distrust of their care and intentions.

Matthew (2015) says; The diagnostic sorting process, called making a differential diagnosis, requires doctors to use familiar patterns and generalizations about people and their maladies to correctly identify, understand, and address illness. Certainly, considerations of race

and ethnicity can be relevant to this process as other categorizations such as age and weight.” (Matthew, 39) Although these patterns and generalizations can be useful, what can creep in is implicit biases that stereotypes a person rather than provides her or him with the proper care. The need for a paradigm shift in care in Brownsville must involve an intentional re-structuring of what it means to engage its majority African American community and its provisions to provide quality care to minorities.

In an evaluation done by The University of Tennessee Knoxville, after the closing of Haywood County Community Hospital, entitled *Hurdles to Healthcare: Overcoming Health Access Barriers in Haywood County, Tennessee*, Wilt et al. (2018) spoke about some of the barriers that needed to be addressed in order to provide equitable healthcare in Haywood County. They conducted a project to gain feedback from the community about the closing of the hospital. They used focus group meetings and voluntary online surveys in order to gain insight of which a small group of about 25 participants attended in person and 46 responses were from the surveys. (Wilt et al, 4-5) They identified problems with lack of awareness of healthcare resources, transportation, access to routine care, emergency transportation, and availability to emergency care and offered potential recommendations and solutions to these barriers.

Though they suggested a 211 call center to access healthcare resources, transportation resources for senior citizens, emphasized the utilization of a local clinic in the area, call screening for emergency services, and the creation of rural partnerships which were very good ideas, one of the biggest oversights was not addressing the distrust that exist particularly in the African American community. Their assessment seemed to come from an analysis of the community not a true engagement of the community. A top-down approach to community

engagement examines surface issues and not the underlying issues that permeate a dysfunctional relationship between African Americans and the medical community. When talking with people from the community churches, local stores, barber shops and hair salons, places where people discuss their frustrations as well as joys, there is this sense that the medical community only wants to engage with African Americans when they want to use them as “guinea pigs”.

One barber says; “They have been experimenting on us for years. They’ve been using us as guinea pigs.” Those in black churches experience a similar feeling when they express, “The only time they come to us is when they need us to do something.” These feelings of discontentment come when the African American community seems to be an afterthought rather than being a stakeholder at the table. Building a trusting relationship with African Americans is important if you want cooperation and participation from the African American community. Kennedy et al. (2007) states; “Distrust of the health care system by African Americans runs from the feelings of ill gains for participation in clinical trials to being used only as guinea pigs.” (Kennedy et al., 57)

In a study done by LaVeist et al. (2000), “When read the statement “Patients have sometimes been deceived or misled at hospitals,” 51.4 percent of black patients agreed or strongly agreed compared to 42.4 of white patients.” (LaVeist et al., 152) Additionally, when read the statement “Hospitals have sometimes done harmful experiments on patients without their knowledge,” 50.6 percent of blacks compared to 26 percent of whites felt that experiments had been done without patient’s knowledge. (LaVeist et al., 152) Furthermore, Durant et al. reported; “African Americans were more likely than whites to think that they could potentially be “used as guinea pigs” without giving their permission (54% vs 28%,  $p \leq .0001$ ) or to think

that health care providers, in general, prescribe medications as a way of “experimenting on people without permission” (60.0% vs 40.6%,  $p \leq .0001$ ) (Durant et al., 2011)

What can be ascertained from the authors above is a deep rooted sentiment of distrust that cannot be resolved from a top-down model of engagement with the African American community. There has to be an interpersonal relationship that allows African Americans to discuss and express their feelings of distrust openly and those feelings to be acknowledged and affirmed. This kind of relationship of trust does not happen at an occasional health fair or other isolated community events; rather, this type of relationship happens when resources, talent, and time are invested to assure a constant presence in the community. Citing Dilworth-Anderson, 2011, Murray (2015) writes; “It is important to realize that trust develops over time. While one interaction impacts whether trust is lost or maintained, trustworthiness is developed over time, that is, with recurring interactions where an individual remains willing to depend on another to meet a need because expectations have continuously been met.” (Murray, 290)

The Coronavirus Pandemic of 2020 exposed not only the disparities in healthcare for African Americans but also the heightened distrust of African Americans concerning research and vaccinations. As of March 26 2021, it is estimated that there have been over 29,976,179 cases of COVID-19, 545,273 deaths, and an estimated 140,000,000 vaccinations in the United States. ([www.covid.cdc.gov](http://www.covid.cdc.gov)) In Haywood County, there have been 2660 cases of COVID-19, 60 deaths, and 2,198 vaccinations. ([www.covid.cdc.gov](http://www.covid.cdc.gov)) COVID-19 has put a tremendous strain on small rural communities where the availability of healthcare is scarce. In Haywood County, those who were severely affected by COVID were usually hospitalized in nearby Jackson, Tennessee. African Americans, in particular, were hit hard in Haywood County and we lost

people who were greeters at our local Wal-Mart, classmates of my wife, and sadly, a young man that I mentored from the barbershop I go to every week. The ages of these individuals ranged from 27 years old to 45 years old. Families were devastated and communities left in disarray due, in part, to misinformation and the lack of information. Also, their occupations put them at risk because they worked for local manufacturing companies, food industries, or grocery stores which put them at a higher risk for exposure.

There was a push to enlist minorities in research efforts to curb this terrible illness. However, the skepticism about the political motivations of the last administration and the seemingly, “by the way, the lead researcher for the vaccine is an African American woman” play to get African Americans to trust the vaccine did not sit well with some in the African American community. African Americans were not fully involved in the process of dealing with this pandemic until researchers needed more minority support in research studies and vaccinations. Ironically, African Americans are not against research or vaccinations but require an open, informative dialogue where their questions and concerns can be answered. The failure in The Tuskegee Syphilis and the use of Henrietta Lacks’ cancer cells was the lack of disclosure and informed consent which violated their autonomy to make an informed decision about their participation in these research studies. In fact, when Corbie-Smith et al. (1999) addressed barriers to African American participation in research studies, they state; “When asked how participation in research might be improved, participants expressed the need for more honest and respectful communications from physicians and other research personnel and the importance of providing complete information about risks and benefits of research.” (Corbie-Smith et al., 541)

Cornell Belcher (2021) argues that the hesitancy to take the vaccine is not because people do not want it but because of the lack of information. In a survey of 1,511 Black, Hispanic, Filipino, Vietnamese, and Native Hawaiian adults, Belcher found that 47% of African were more likely to take the vaccine based on the information they received versus 22% who were less like to take the vaccine. When asked if the vaccine were ready today at no cost would take it, 67% said they would take it and 14% said they would not. (retrieved from nul.org) What Corbie-Smith et al. and Belcher show is distrust can be overcome if honest communication, information sharing, and engagement with the African American community is established. The disheartening fact is that African Americans seem to be an afterthought until there is an absolute need for their participation. Having a consistent presence in the African American community is key in battling devastating illnesses and enlisting African Americans in research studies. Health fairs and occasional community events are not enough to build trust. If the medical community wants to build trust with the African American community, there has to be an intentional effort to build interpersonal relationships that transcend the hospital or medical office. Sullivan (2020) believes:

To require individuals from a group that has historically been the subject of exploitation and discrimination to resolve the issue of mistrust in American medicine is to further burden them, exacerbating injustice. If the problem of mistrust in American medicine is to be resolved, the task must be taken up by those who would like to be seen as trustworthy. (Sullivan, 19)

If there is to be a change in how the African American community responds to the medical community, there has to be a concerted effort to address the distrust that has been caused by institutions and systems that have perpetuated the continuation of policies and treatments that further accentuate the gulf between trust and distrust. What would this look like from a standpoint of practical application?

## Chapter 4. A Paradigm for Praxis: Community Connect

In 2007, the Methodist Healthcare System, in Memphis, Tennessee, started what is known as the Congregational Health Network, under the leadership of Dr. Gary Gunderson, in response to the poverty and health care inequities that was ravishing the inner-city population of Memphis. They noticed many African Americans were disproportionately dealing with advance stage diseases in their early twenties and thirties. Illnesses such as congestive heart failure, diabetes, hypertension, kidney disease, and obesity. Teresa Cutts, who was in charge of evaluating the Congregational Health Network, calls the city's high rate of chronic diseases mentioned above as a "chronic co-morbidity cocktail." (Halperin, 2013, 5) The result was a "covenant committee" of 12 pastors who met with the leadership of Methodist to design a system that would target health disparities in the community and create better access for the community to receive health care. ([www.stakeholderhealth.org](http://www.stakeholderhealth.org))

Former Director of Faith and Health, Rev. Dr. Bobby Baker, outlines how Methodist and its covenant partners sought to address the issues of health care disparities and community access to health care. He explains:

We set out to do that in five ways. First, we were going to educate the community on health issues and how to access the healthcare system and the existing resources. Second, we wanted every congregation to have some kind of prevention going on in their congregation. Third, we designed an intervention program for the congregation to be a part of the care for their members while they're in the hospital and after they're discharged. Fourth, we created an access program that helps people navigate the healthcare system and the health care they need. Finally, we asked all of our congregations to be involved in aftercare. ([www.stakeholderhealth.org](http://www.stakeholderhealth.org).)

As a result, the hospital invested in hiring navigators who would be responsible for connecting with congregations. Pastors signed covenants and agreed to partner with Methodist Healthcare and provide liaisons who would work with hospital navigators to implement the

program. The program signed up to date over 500 churches, the majority being African American churches, from various denominational backgrounds. The Congregational Health Network (CHN) enlists members from those covenant churches and the pastors and members receive discounts for being a part of the network. “Methodist says CHN costs it about \$1 million per year to run, not including outside grants, and saves the hospital \$4 million in annual costs.” ([www.salon.com](http://www.salon.com)) The success of the program comes as a result of incorporating community churches and clergy whose influence helps inform parishioners about the benefits of their health and access to health care.

For African American communities, the essentiality of the church and her leadership plays a major part in how information is received and disseminated into the black community. Eiser and Ellis (2007) recognize the importance of the black church and her leaders when it comes to health and health outcomes. They state:

Many African Americans have either a religious orientation or a viewpoint grounded in African American social and cultural history, which may emphasize a holistic approach to health and health care. Religion is a source of enormous emotional support for African Americans, and religious observance and religiosity, in many regards, correlate with improved outcomes. (Eiser & Ellis, 177)

What Eiser and Ellis highlight is the centrality of religion to the African American community and experience. For African Americans, there is not any separation between the sacred and the secular; but, they are intertwined to address the economic, health, social, and religious realities that they face. The wisdom of the CHN was to ground their service to the community through the church. During slavery, religion was a key component in the everyday life of slaves. When distrust permeated their relationship with the slave-owners and the medical community, the church became the place of healing of the mind, body, and soul. African

American pastors bore the burden of being servant leader, shepherd, administrator, counselor, advocate, etc. Harmon et al. (2018) point out; “A pastor in an African American church was far more than... someone who teaches or preaches. If you go back to African culture, you’re almost a tribal leader, and so that tradition sort of continues.” (Harmon, et al., 1512) Still today in rural churches in West Tennessee, pastors are looked upon as being the one to go to find out about anything relevant to the church, health, or society.

The uniqueness of the black church is her ability to pool together resources as well as distribution of those resources. This is particularly important when we deal COVID-19 and the potential vaccinations of African American parishioners. When the rollout of vaccines happened at the beginning of 2021, African American churches and her pastors were solicited as hubs for the distribution of the vaccines. One of my close friends, who is a pastor in a rural community, used his church as a location for COVID vaccines. He was overjoyed to see the response from the medical community and the response from the parishioners and community. There were about 100 people who were vaccinated. Therefore, the power of the black church to make significant strides in helping people regain trust in the medical community requires intentional actions on the part of the medical community to be present and available to the African American community.

The CHN made tremendous strides in bridging the gap between the hospital and the church in Memphis. However, one of the shortfalls of CHN was its lack of engagement with the rural communities who also are consumers with the Methodist Healthcare system. By limiting its scope to communities and community leaders in Memphis, the CHN has missed a great opportunity to expand its message and mission to outlying rural communities. This is where

Community Connect can help pick up the pieces. I argue that Community Connect can not only expand the concepts of CHN but make it more context centered where stakeholders can feel more involved in the plan and process of connecting resources to county residents.

Building on the analysis done by Wilt et al., the proposed plan of Community Connect will be based on an interesting book I discovered when I pastored a small rural congregation that grew from 7 members to over a 160 members. The book was entitled *Finding Them, Keeping Them: Effective Strategies for Evangelism and Assimilation into the Local Church* by Gary McIntosh and Glen Martin. What struck me about this book was it challenged church leaders to examine how they engaged the community from a standpoint of evangelism. They ask the question; “Have you ever wondered why a pigeon walks so funny? A pigeon walks the way it does so it can see where it’s going. Since a pigeon can’t adjust its focus as it moves, it actually has to bring its head to a complete stop between steps in order to refocus.” (McIntosh & Martin, 1992, 9) They argue in order for the church to grow she has to learn how to take steps forward, but also, stop, evaluate where she is, and refocus before continuing her forward progress.

Although its primary audience was the church, the steps to engage potential believers can be used to bridge the gap between the African American community and the medical community. Since we have discussed how important the black church is to the African American community, the strategies offered by McIntosh and Martin can be assimilated into Community Connect as a means of connecting stakeholders whose visions of holistic healthcare may be at odds with each other. McIntosh and Martin offer five strategies for evangelizing potential believers. The five strategies are: 1. Be present in your community, 2. Proclaim the Gospel, 3. Persuade people to accept Christ, 4. Help people progress in the Christian life, and 5. Help

people produce new believers. (McIntosh & Martin, 13-15) Learning from Wilt et al.'s hurdles to receiving healthcare in Haywood County, the mission and vision of the Congregation Health Network (CHN), and the strategies of evangelism by Gary McIntosh and Glen Martin, Community Connect will function on the community strategies outlined below.

#### Strategy One: Establishing a Presence in the Community

It has already been stated that being an active part of the community is vital to building a connection to the community. For the African American community, simple health fairs and occasional community events are not enough. Being present is not about dumping resources but about showing a genuine concern for the community in which one serves. Being an active participant in cultural and social functions, volunteering to assist in church related events, and informal interactions with the African American community builds trust and meaningful relationships that transcend the formal patient-physician or researcher and research participant relationship. (Huang & Coker, 2010, 631) There is a need to have an interpersonal relationship where the community residents feel safe to share their concerns regarding their health and subsequent decision-making. Similar to CHN, having a neighborhood liaison from the medical community to connect with church leaders will lessen distrust and improve the skepticism people may feel from just seeing someone from the medical community on rare occasions. Building a relationship of mutuality requires active listening for the concerns of the community which may not be transparent through normal conversations. This type of interaction is casual and non-threatening. In establishing a presence in the community, the primary objective is to become familiar with community, its culture and customs. McIntosh and Martin (1992) would suggest identifying the needs of the community and parallel the needs of the community with programs that meet those needs. The strategy here is to allow the community to be the focus and not the

one offering the service. Need-based programs come from being a part of the everyday activities and lives of the community.

### Strategy Two: Information and Resource Sharing

Once there has been an established presence in the community, it opens up an opportunity to share information and resources that the community may need but would not have been open to without a consistent presence. This is where actively listening to the concerns of the community in a non-judgmental and non-threatening way allows one to assimilate those concerns into sharing information and resources which may benefit the community based on what they shared in a casual setting. McIntosh and Martin would call this step in evangelism proclamation but for the purpose of Community Connect it is information and resource sharing. Your presence produced the opportunity to share. Without being present, the information and resource portal could have been rejected. Oftentimes, information is rejected because it comes from a top-down paternalistic approach that isolates rather than invites those in the African American community to be a stakeholder.

The “we know what’s best for you” approach to information sharing comes off as condescending and disingenuous. However, when there is a mutual sharing in which the medical community shares vital information for the health and wellbeing of the community and the African American community shares its beliefs, customs, and concerns when it comes to healthcare, a relationship of equality and reciprocity emerges and the medical community is no longer looked upon as an adversary but an ally. The information and resources sharing can be done during informal events within the community where persons religious or non-religious can ask questions of physicians regarding certain illnesses, in collaboration with church educational

forums such as district associations that focuses on Christian Education training and educational resources in general, or through small group sessions where board members and community leaders come together. The purpose is to get as much information as possible into the community to deal with the healthcare disparities and socio-economic inequities that affect African American communities. It cannot be overstated about the importance of working closely with African American pastors and churches. With the support of pastors and churches, the opportunity to have a constructive dialogue with the community offers many avenues of growth for the community and for the practitioners.

#### Strategy Three: Community Forums

The strategy here is to see how information that has been shared is being processed and to address any assumptions or misinformation regarding healthcare resources and/or treatment options. Community forums are very important when it comes to establishing trust because it gives voice to the community to freely challenge information that has been given without the recourse of feeling intimidated due to an established relationship. This allows the medical community the opportunity to check any assumptions it may have about the community and to listen the stories that may have been overlooked. This would be a great chance to incorporate narrative ethics, which values the stories of people and their care, to understand how the story of the community affects the medical choices they make. Here questions and answers to clarify what resources are needed in regards to transportation, emergency services, healthcare concerns, etc. can be filtered through these community forums. The expectation is that by building a presence and relationship with the community that distrustful barriers are being torn down and trusting relationships are developing. McIntosh and Martin would call this strategy in their work persuasion evangelism. Persuasion, in their analysis, hinges on moving one to a decision about

one's faith. (McIntosh and Martin, 39-40) For Community Connect, it is about moving one to a dialogue in order to affect the masses with credible information and resources to affect healthcare disparities within the community.

#### Strategy Four: Community Ownership

At this point, the hope is the community has established a relationship of trust with the medical community in the area, has had their questions and concerns addressed and answered, and are now ready to be conduits of information for others in the community. This is where CHN's framework for utilizing resources within the church and community to be liaisons between the hospital, the church, and community can be most beneficial. Soliciting lay members to volunteer to be a channel to communicate concerns and questions of the community to the medical community so the connection continues to be a viable source for addressing the needs of the community. Partnering with churches helps to facilitate ownership by allowing a grassroots approach to community ownership rather than a top-down approach.

In their book, McIntosh and Martin would call this strategy progression evangelism. From an evangelistic standpoint, progression would deal with believers in the faith progressing in their knowledge about Christianity. (McIntosh & Martin, 44-49) However, for Community Connect, the progression deals with limited influence from the medical community and more influence from stakeholders in the community. Pastors and identified liaisons work with other community organizations to hold each other accountable for organizing forums, Sunday morning lectures on health issues for the church and community, and the expansion of volunteer recruitment. Now, trust is a shared venue because the medical community entrusts the pastors, churches, and community leaders to communicate the needs of the community in a continuous

effort to provide resources and services and the community trusts the medical community to be forthcoming with any new information that affects the health and wellbeing of the community.

#### Strategy Five: Re-visiting the Process: SWOT Analysis

At this juncture, it would be wise to re-visit how the plan of action came together and see if any improvements can be made. A SWOT analysis deals with observing the strengths, weaknesses, opportunities for growth and threats. A SWOT analysis is a great way to restructure a program without dismantling its foundation. In the case of Community Connect, one would want to examine if there was a sufficient presence in the community by doing a qualitative study of the community to see the effectiveness of the need-based programs designed for the community. Key questions to ask among community leadership are: Does the community feel that the medical community has invested enough time and resources to affect change in the community? Does the community see the medical community as an asset or adversary? What, if anything, could be improved with the interaction between the medical community and the African American community? Does the African American community feel a stronger bond of trust with the medical community? Lastly, have there been sufficient opportunities for the African American community to access healthcare resources?

These are just several questions to consider when evaluating the partnering relationship between the African American community and the medical community. McIntosh and Martin would consider this strategy production evangelism because the focus is on helping others produce other learners. (McIntosh & Martin, 53-54) Community Connect uses this strategy to inform it of how to continue a cycle of volunteerism where the work is so important to the community that obstacles discovered in the SWOT analysis becomes an opportunity of

redirection and recommitment to the work of a trusting and resourceful community. The SWOT analysis produces new possibilities to examine blind spots, restructure the format, and redirect resources if needed in order to reach a wider range of potential community advocates and volunteers. The continual movement of Community Connect hinges on making sure that needs are met in a responsible and equitable way.

## Chapter 5. Moving Forward

To this point, we have discussed the historical perspective of African American distrust based on the triadic relationship between slavery, law, and the medical community's involvement in oppressive actions and experimentations which gave rise to the distrust in the African American community, we further discussed why there is need for a new paradigm that re-examines the relationship between the medical community and the African American community, particularly in rural communities, as well as a paradigm for praxis that offered strategies for bridging the gulf between trust and distrust that exists in rural African American communities. Moving forward, Community Connect is in its infancy and requires additional conversation with stakeholders to become an active part in the Haywood County community.

There has been email communications with Kyle Kopec, who is CCO/Director of Government Affairs for Braden Health, about developing this project and its potential usefulness for the Brownsville/Haywood County community. Braden Health is the company responsible for re-opening the hospital in Haywood County. Also, communication has taken place with local pastors in the African American community to discuss what community connect would look like and their support of this project. Since I have a previous clergy relationship with most of the pastors in this area, it would not be difficult to garner the support needed for Community Connect. Ultimately, we want to further design a qualitative survey to gain feedback from the community to assess their willingness to participate in the grassroots organizing of Community Connect's mission and vision going forward. Once the feedback from the community is received, we would organize a meeting between the stakeholders in the community and Braden Health. With a voice at the table, the goal is to mitigate any distrust from the beginning so that we can

contribute to the viability of Braden Health's mission to bring together the hospital and the community, especially, the African American community.

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