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EXAMINING THE “STICK” OF ACCREDITATION FOR MEDICAL SCHOOLS THROUGH REPRODUCTIVE JUSTICE LENS: A TRANSFORMATIVE REMEDY FOR TEACHING THE TUSKEGEE SYPHILIS STUDY

DELESO ALFORD WASHINGTON*

*False And What About The Women Of the Tuskegee Syphilis Study?*¹

The Tuskegee Syphilis Study was never really a study to find the answer or even an end to the disease of racist and race-based science that hides the truth from all mankind.

It left out the women who wore race – with tight lips and heavy hearts, dresses often ironed and sometimes torn, yet laced with lies and questions

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¹ An original previously unpublished poem was written by Author and dedicated to the memory and lives of the women of the Tuskegee Syphilis Study.

that made living with silenced pain just another aspect of bearing children and being born.

Today, may the women of the Tuskegee Syphilis Study be seen and heard claiming their space as those of us compelled to tell ‘her-story,’ empower and inform the human race.

INTRODUCTION

First, it is important to note that the “The Tuskegee Study of Untreated Syphilis in the Male Negro”² is the original name for the study that is commonly known as “The Tuskegee Study.”³ The shortening of the official name of the study not only diminishes the truth behind “untreated syphilis” and specific targeting of a gender and racial group (“the male negro”), but, it also speaks to the need to address Black women and the Tuskegee Syphilis Study. This omission of Black women in the legal, medical, and historical narratives of the Tuskegee Study illustrates the marginalization of Black women in medical research and education, which this Article seeks to address. Therefore, this Article will address a traditionally overlooked, historically marginalized and devalued aspect of our society: women in general and in particular, Black women, specifically in relation to healthcare, research and medical education.

The Tuskegee Syphilis Study,⁴ like the traditional recounting of the event, failed to acknowledge the direct impact of untreated syphilis in women. Arguably, the most infamous biomedical research study ever performed by the United States government is the Tuskegee Syphilis Study, which occurred between 1932 and 1972 in Macon County, Alabama.⁵ The stated purpose of the Tuskegee Syphilis Study was to determine the effects of untreated syphilis on Black men in Macon County, Alabama.⁶ Accordingly, historical and legal accounts have primarily told the stories of

² R.A. Vonderlehr, Taliaferro Clark, O.C. Wenger & J.R. Heller, *Untreated Syphilis in the Male Negro: A Comparative Study of Treated and Untreated Cases*, 107 JAMA 856-60 (1936). See Centers for Disease Control and Prevention, U.S. Public Health Service Syphilis Study at Tuskegee, available at <http://www.cdc.gov/tuskegee/timeline.htm>.

³ JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT 1* (1993).

⁴ FRED. D. GRAY, *THE TUSKEGEE SYPHILIS STUDY: AN INSIDER’S ACCOUNT OF THE SHOCKING MEDICAL EXPERIMENT CONDUCTED BY GOVERNMENT DOCTORS AGAINST AFRICAN AMERICAN MEN 13* (1998) (noting that “[a]s attorney for the participants in what became known as the Tuskegee Syphilis Study” he was deeply moved by President Clinton’s White House apology for “one of the most shameful episodes in U.S. medical history”).

⁵ *Id.* at 48 (discussing the “phases” of the study in great detail).

⁶ *Id.*

the male participants of the Study.⁷ However, an overlooked yet important question looms: What about the women of the Tuskegee Syphilis Study? To date, there have not been consistent and adequate substantive challenges to the omission of the women affected by the study, whether in historical accounts or contemporary bioethical discourse.⁸ This Article fills the gap in this historical and contemporary omission by calling for a reproductive justice framework to not only critically examine the Tuskegee Syphilis Study, but also to offer curricular content on cultural competency to aid medical schools in their quest to attain accreditation. This approach engenders an identifiable “space” that acknowledges the Black women who also sustained injuries from the Tuskegee Syphilis Study and centers the reproductive health issues pertaining to women of color in a medical educational setting that will “respond to the need to ensure that all people entering the health care system receive equitable and effective treatment in a culturally and linguistically appropriate manner.”⁹

Medical schools must deliver a culturally competent curriculum for purposes of accreditation. This article will shed light on race, gender, and class disparities in healthcare. Specifically, I will address the marginalization of women in the historical and contemporary recounting of the Tuskegee Syphilis Study. This Article contends that the Tuskegee Syphilis Study’s failure to acknowledge the direct impact on women requires a transformative remedy to address cultural competence accreditation mandates for medical education.

Section I critically examines the Tuskegee Syphilis Study. Section II focuses on current medical schools’ accreditation standards on cultural

⁷ See *supra* notes 4 and 5; See also, KARLA FC HOLLOWAY, PRIVATE BODIES, PUBLIC TEXTS: RACE, GENDER, AND A CULTURAL BIOETHICS 113-114 (2011) (noting the Tuskegee narrative’s preeminence in the public nature due to the involvement of black male sexuality, race and disease).

⁸ Others have written about the absence of the wives in the recounting of the impact of the Tuskegee Syphilis Study. See Vanessa Northington Gamble, *The Tuskegee Syphilis Study and Women’s Health*, 196 JAMWA Vol. 52, No. 4 (Fall 1997) (noting that the “[t]he Tuskegee Syphilis Study affected wives in other ways. As the men in the study suffered from the ravages of the disease, their wives assumed traditional caretaker roles. These women also shared in the emotional pain on learning that their families had been betrayed by institutions they trusted.”); see also Evelyn M. Hammonds, *Your Silence Will Not Protect You: Nurse Rivers and the Tuskegee Syphilis Study*, in TUSKEGEE’S TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY 340, 341 (Susan M. Reverby ed., 2000) (critically examining the Tuskegee Study and the official role of Nurse Rivers, and noting that Nurse Rivers was not the only woman who had to deal with the consequences of the study – asking questions such as: “What of the wives of the men [involved in the study]? How many of them were put at risk because of the failure to treat the men? And most importantly, what are we, as African-American women, to make of various attempts to cast Nurse Rivers as a collaborator in one of the most unethical medical studies of this century?”).

⁹ Preamble, National Standards for Culturally and Linguistically Appropriate Services in Health Care, Final Report issued by the U.S. Department of Health and Human Services (HHS) Office of Minority Health (March 2001, Washington, D.C.).

competence, and their stated criteria. Finally, Section III explores the notion of a reproductive justice framework that will serve as a transformative remedy to address current medical education accreditation standards. The implementation of an inclusive curricular content that acknowledges the direct impact of the women in the Tuskegee Syphilis Study can serve as a step toward addressing a historically accepted omission that impairs the ability of medical schools to satisfy current cultural competence accreditation standards.

I. THE TUSKEGEE SYPHILIS STUDY REVISITED

*The ultimate lesson that many Americans saw in the Tuskegee Study was the need to protect society from scientific pursuits that ignored human values.*¹⁰

A critical examination of the most widely disseminated papers, books, reports and other written documents about the Tuskegee Study reveals that the “Study” was misleading in its purpose as well as its method of securing participants.¹¹ According to James H. Jones, “[t]he Tuskegee Study had nothing to do with treatment. No new drugs were tested, nor were any efforts made to establish the efficacy of old forms of treatment. It was a nontherapeutic experiment, aimed at compiling data on the effects of the spontaneous evolution of syphilis on black males.”¹² This section will explore how the data was compiled by assessing the institutions involved, the selected human subjects, and duration of the experiment in order to contextualize the biomedical significance¹³ of the Tuskegee Syphilis Study.

¹⁰ JONES, *supra* note 3, at 14.

¹¹ HARRIET A. WASHINGTON, *MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* 157 (2006) [hereinafter WASHINGTON, *MEDICAL APARTHEID*] (stating that “[The U.S. Public Health Service] lied to the subjects, convincing them that they were being treated, not studied”); W. MICHAEL BYRD & LINDA A. CLAYTON, *AN AMERICAN HEALTH DILEMMA: RACE, MEDICINE, AND HEALTH CARE IN THE UNITED STATES 1900-2000* 16 (2002) [hereinafter “BYRD & CLAYTON, RACE, MEDICINE, AND HEALTH CARE”] (noting that “the Tuskegee medical researcher deceptively told the men they were being treated”); JONES, *supra* note 3, at 5 (quoting Dr. J.W. Williams, who served as an intern at Andrews Hospital at Tuskegee Institute in 1932 and gave a first-hand account regarding what health officials told the men involved in the study: “We didn’t tell them we were looking for syphilis”); GRAY, *supra* note 4, at 24 (pointing out that “effective treatment was knowingly and systematically withheld from those suffering with a potentially fatal disease”).

¹² JONES, *supra* note 3, at 2.

¹³ *Id.* at 91 (noting that the Tuskegee Study of Untreated Syphilis in the Negro Male is the longest non-therapeutic experiment on human beings in medical history).

*A. The Institutions – In Black and White*¹⁴

There is a fundamental question that should be posed when reconsidering a historical event such as the Tuskegee Syphilis Study: "How could this episode, requiring the collaboration of doctors, county and state health departments, draft boards, and the U.S. Public Health Service, ever have occurred? As noted historian Allan Brandt suggests, the Tuskegee study must be understood with regard to the "essentially racist nature of the experiment."¹⁵ The horrific nature of the study, along with its intended and collateral consequences, is "especially appalling because it was officially sanctioned by the federal government and involved life or death situations for several hundred United States citizens."¹⁶ Brandt argues that, [t]he experiment was based upon two essentially racist precepts. First, the doctors who designed the study believed that virtually all southern blacks were infected.

A closer examination of the institutions involved, the U.S. public health care system, the parties affected, and the location of the Tuskegee Syphilis experiment supports an accepted practice of "scientific racism that pervades American health institutions, historically and contemporaneously, and reflects the devaluation of Black human rights and lives in the health system."¹⁷

The federal government's effort to address venereal disease, including syphilis, began in response to the returning veterans from World War I.¹⁸ Treatment for syphilis that would reach poor, rural communities such as Macon County, Alabama came in the form of an alliance between the

¹⁴ Vonderlehr et. al., *supra* note 2, at 856 (stating that the first published report on the Tuskegee Syphilis study was "[r]ead before the Section on Dermatology and Syphilology at the Eighty-Seventh Annual Session of the American Medical Association, Kansas City, MO, May 15, 1936"). See GRAY, *supra* note 4, at 85-86 (explaining that Nurse Eunice Rivers Laurie and the Tuskegee Institute were not named as defendants in the 1973 class action lawsuit because the lone African American female nurse and the financially struggling African American educational institution and its officials were "misled, betrayed, and taken advantage of" by the federal government).

¹⁵ Allan M. Brandt, *Racism and Research: The Case of Tuskegee Syphilis Study*, in TUSKEGEE'S TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY 15, 27 (Susan M. Reverby ed., 2000) [hereinafter Brandt, *Racism and Research*]; BYRD & CLAYTON, RACE, MEDICINE, AND HEALTH CARE, *supra* note 11, at 16 (referring to the Tuskegee experiment as "unethical and exploitive").

¹⁶ GRAY, *supra* note 4, at 24 (explaining how Fred D. Gray became involved as the Attorney of record for the plaintiffs in the 1972 class-action lawsuit filed on behalf of the men who were participants in the Tuskegee Syphilis Study).

¹⁷ BYRD & CLAYTON, RACE, MEDICINE, AND HEALTH CARE, *supra* note 11, at 418. See F.N. Boney, *Slaves as Guinea Pigs: Georgia and Alabama Episodes*, 37 ALA. L. REV. 45 (1984) (exploring two medical episodes in antebellum Georgia and Alabama to conclude that Slavery was indeed a "peculiar institution" and that historians do not fully understand its modern impact on human experimentation).

¹⁸ GRAY, *supra* note 4, at 39.

philanthropic Rosenwald Fund¹⁹ and the U.S. Public Health Service (PHS), which sought to “expand medical services to the poorest African American areas of the South.”²⁰

The Rosenwald Fund division that supported syphilis-control demonstration programs was established in November 1929.²¹ The Rosenwald Fund’s connection to the Tuskegee Institute (now Tuskegee University),²² was seldom discussed in the broader context of the Tuskegee Syphilis Study, but played an important role in regards to the level of trust within the community surrounding free medical treatment from doctors during health demonstrations.²³ In January 1930, the Fund began demonstration programs in Macon County, Alabama and five other sites recommended by the PHS.²⁴ The initial experiment funded by Rosenwald exemplified the greatest kindness.²⁵ The result of the Rosenwald Study confirmed that mass treatment could be successfully implemented among rural blacks.²⁶

In May 1930, Dr. H.L. Harris, Jr., a Black physician employed by the

¹⁹ Julius Rosenwald, a Jewish philanthropist responsible for helping to build the Sears and Roebuck Company mail order business, “sought to improve race relations in general as well as the specific health and social problems facing African Americans in the Southern states.” Starting in Macon County, Alabama, the Rosenwald Foundation provided funding for the construction of a large number of schools in the south. GRAY, *supra* note 4, at 38-39.

²⁰ *Id.* at 39.

²¹ See Susan E. Bell, *Events in the Tuskegee Syphilis Study: A Timeline*, in TUSKEGEE’S TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY 34, 34 (Susan M. Reverby ed., 2000) (listing the Rosenwald Fund’s November 1929 vote regarding “syphilis-control demonstration programs” as the first event on the timeline of the Tuskegee Syphilis Study); see also JONES, *supra* note 3, at 59-60 (describing the November 1929 events as follows: “The trustees [of the Rosenwald Fund] voted . . . to spend up to \$50,000 during the 1930 calendar year ‘for demonstrations of the control of venereal disease in the rural South, in cooperation with the United States Public Health Service and with the state and local authorities.’”).

²² GRAY, *supra* note 4, at 39 (noting that Julius Rosenwald became a patron of Booker T. Washington and the Tuskegee Institute).

²³ See CHARLES S. JOHNSON, *SHADOW OF THE PLANTATION* 202 (Transaction Publishers 1996) (1934). Johnson, in a discussion of community attitude, explains that the experiment was probably the most successful health demonstration with regard to getting a large number of people to have blood tests. See generally JONES, *supra* note 3, at 68 for a discussion of the book *Shadow of the Plantation*. Charles S. Johnson, the author, is a famous black sociologist and President of Fisk University. It is noted that “[t]he book was commissioned by the Rosenwald fund because [Michael M. Davis, Director of Medical Services] wanted a sociological analysis of the blacks who participated in the syphilis control demonstrations.” Jones also mentions that the book, in part, explores the reasons why blacks in the Deep South were eager participants in the program.

²⁴ Bell, *supra* note 21, at 34. The United States Public Health Service’s recommendations for program locations included: Macon County, Alabama; Scott County, Mississippi; Tipton County, Tennessee; Glynn County, Georgia; Pitt County, North Carolina; and Albemarle County, Virginia. *Id.*

²⁵ JOHNSON, *supra* note 23, at 202. The significance of Charles S. Johnson’s study is that it is a “multi-faceted interpretive survey of the 612 black families that composed the rural community of Macon County, Alabama, in the late 1920s and early 1930s.” Joseph S. Himes, *Introduction to CHARLES S. JOHNSON, SHADOW OF THE PLANTATION* ix (Transaction Publishers 1996) (1934).

²⁶ Brandt, *Racism and Research*, *supra* note 15, at 27.

Rosenwald Fund, conducted a site visit to evaluate the syphilis control demonstrations and reported that the people "were entirely ignorant of the character of disease for which they were being treated."²⁷ It appears that "[p]ublic health officials announced that they had come to test people for "bad blood."²⁸ First-hand accounts from individuals indicate that "bad blood" was an accepted term in the community that referred to many different ailments – without any social embarrassment of a disease.²⁹ In fact, among the over 600 families that Johnson interviewed for his book, *Shadow of the Plantation*, there was no connection of syphilis to a sexual act.³⁰ The condition of "bad blood" was spoken of in the same manner as one speaks of having a "bad heart" or "bad teeth."³¹

In the Fall of 1930, Dr. Harris' second report noted that some 1,271 cases of syphilis had been brought under treatment in the six clinics that were operating in Macon County.³² However, by the end of the site visit, Dr. Harris did not recommend that the syphilis control demonstration in Macon County continue, because it had "accomplished practically all that can be hoped from it."³³ The alleged success of the Rosenwald Fund experiment lies in the eyes of the beholder. Attorney Fred Gray puts it best, "[t]he Rosenwald/Public Health Service projects during 1930-31 were almost too successful. Approximately forty thousand persons were tested for syphilis in the six counties surveyed, and 25 percent were found to be infected."³⁴

Despite the harsh realities of Dr. Harris' final report, it appears that the notion of any treatment or care by a physician garnered a degree of benevolence from the people of Macon County.³⁵ The doctors and researchers involved saw Macon County as a prime opportunity to study *untreated* syphilis.³⁶ The men, women, and children who stood in long lines seeking treatment for their ailments maintained an "attitude of appreciation for the gesture of helpfulness which the demonstration

²⁷ JONES, *supra* note 3, at 71.

²⁸ *Id.*

²⁹ JOHNSON, *supra* note 23, at 202.

³⁰ *Id.* at 201.

³¹ *Id.*

³² JONES, *supra* note 3, at 82.

³³ SUSAN M. REVERBY, EXAMINING TUSKEGEE: THE INFAMOUS SYPHILIS STUDY AND ITS LEGACY, Appendix A, Chronology (2009) (noting that in the Fall 1930, Dr. Harris recommended that the project be discontinued and a comprehensive health plan be implemented).

³⁴ GRAY, *supra* note 4, at 33.

³⁵ JONES, *supra* note 3, at 71 (noting that some of the Macon County residents had never been seen by a physician).

³⁶ *Id.* at 42.

represented. . . . Many of the families [were] enthusiastic in their praise of the work being done by the clinic.”³⁷ This is evidenced by comments made by a wife in a family consisting of a mother, father and ten children who received treatment: “Them shots really hoped [helped] me.”³⁸ However, not every patient was as complimentary. A patient interviewed by Johnson’s team criticized the bedside manner of the “government doctor” that treated him; he recounts: “‘He lay our arms down like he guttin’ a hog,’ the man complained. ‘I told him he hurt me. He told me ‘I’m the doctor.’ I told him all right but this my arm.’”³⁹ Overall, the Rosenwald demonstrations gained positive public support, trust for public health care treatment, and goodwill.⁴⁰ The Tuskegee Syphilis experiment misappropriated this support, trust, and goodwill and ultimately engendered and thereby exploited the Black test subjects by misrepresenting the Study’s intended purpose: not to treat their ailments but to study the effects of *untreated* syphilis.⁴¹

B. The Human Subjects – Intended and Collateral Consequences

The Tuskegee Syphilis Study and its intended consequences should be contextualized in terms of addressing racism, research, and the U.S. healthcare system.⁴² Medical schools typically recount the Tuskegee Syphilis Study, notably the most infamous⁴³ biomedical study in U.S. history, without acknowledging the direct impact on the women who were not part of the study but nonetheless sustained “collateral consequences.”⁴⁴ This omission furthers the existing race, gender, and class disparities in healthcare generally, and specifically the marginalization of women as

³⁷ JOHNSON, *supra* note 23, at 204.

³⁸ *Id.* (noting that the mother, the father, and eight of the ten children gave positive Wassermanns).

³⁹ JONES, *supra* note 3, at 80.

⁴⁰ JOHNSON, *supra* note 23, at 203 (asserting that “good effects observed prompted many to continue treatment and others to seek examination and treatment”).

⁴¹ WASHINGTON, MEDICAL APARTHEID, *supra* note 11, at 157.

⁴² Brandt, *Racism and Research*, *supra* note 15, at 27 (“The first published report of the study appeared in 1936 with subsequent papers issued every four to six years through the 1960s. When penicillin became widely available by the early 1950s as the preferred treatment for syphilis, the men did not receive therapy. In fact, on several occasions, the USPHS actually sought to prevent treatment. Moreover, a committee at the federally operated Center for Disease Control decided in 1969 that the study should be continued.”); ALLEN M. BRANDT, NO MAGIC BULLET: A SOCIAL HISTORY OF VENEREAL DISEASE IN THE UNITED STATES SINCE 1880 158 (1987) (“During the forty years that the Tuskegee Study continued, it was widely reported in medical journals without raising any significant objections on the part of the profession. Indeed, only reports of the study in the general press in 1973 finally brought it to an end.”).

⁴³ JONES, *supra* note 3, at 91.

⁴⁴ Gamble, *supra* note 8, at 341.

research subjects. The historically marginalized issues of race, gender, and research in the Tuskegee Syphilis Study must be acknowledged in order to begin to address current health disparities amongst women.

In order to cast light on the historical marginalization of women impacted by the Tuskegee Syphilis Study, the site and human subjects selected for the study must be critically examined. Dr. Taliafero Clark,⁴⁵ Chief of the PHS Venereal Disease Division and author of the Rosenwald Study, is identified as the lead advocate in the decision to create the Tuskegee Study of Untreated Syphilis in the Negro Male.⁴⁶ Macon County, Alabama,⁴⁷ the chosen site for the experiment - a county with an 82 percent population of Blacks,⁴⁸ a high incidence rate of syphilis,⁴⁹ cooperative local and state officials,⁵⁰ community goodwill, and a unique vulnerability to participate in another Rosenwald-type treatment programs,⁵¹ proved to serve as a "live laboratory." As Dr. Clark reasoned; "[i]f there were no funds to treat the syphilis problem in Macon County, at least a scientific experiment might be a way to learn something from it."⁵² Washington explains that the PHS expected to "validate its belief in a specific racial dimorphism of syphilis . . . it was thought to wreak its worst havoc on the cardiovascular system of Blacks, sparing their relatively primitive and 'underdeveloped' brains."⁵³

James H. Jones correctly points out that "[i]t is necessary to place the Tuskegee Study within its historical and institutional context," and explains how the experiment "fits into the development of the public health movement in the United States."⁵⁴ In order to understand how the Study could have ever occurred and for how long it occurred, one must acknowledge the salience of race and the interaction between race and

⁴⁵ JONES, *supra* note 3, at 54.

⁴⁶ GRAY, *supra* note 4, at 42 (acknowledging that the idea for an observation to study the effects of untreated syphilis could have originated from a number of sources, including Dr. Taliafero Clark since he was responsible for summarizing the Rosenwald surveys, as well as some of the other white doctors who had worked on the project); Brandt, *Racism and Research*, *supra* note 15, at 18.

⁴⁷ See Himes, *supra* note 25, at viii (noting that "Macon County, Alabama, was a cotton farming area of the Black Belt section of a deep South state").

⁴⁸ GRAY, *supra* note 4, at 42.

⁴⁹ Himes, *supra* note 25, at viii (pointing out the Macon County still suffered from the disease even after the death of the plantation).

⁵⁰ GRAY, *supra* note 4, at 42 (stating that the projects were too successful).

⁵¹ *Id.* (explaining that all of the ingredients were there for a successful study).

⁵² *Id.* at 43.

⁵³ See WASHINGTON, *MEDICAL APARTHEID*, *supra* note 11, at 157; see also JONES, *supra* note 3, at 17 (agreeing that "[a]dvocates of racial medicine argued that differences in natural immunity, degree of susceptibility, and relative severity of reaction to various diseases often separated the races").

⁵⁴ JONES, *supra* note 3, at 15.

medicine.⁵⁵

The gender selection for the participants in the Tuskegee Syphilis Study was restricted to males from the very onset, during a meeting initiated by Dr. Clark with members of the “Cooperative Clinical Group, an association of medical researchers composed of the most distinguished syphilologists in the United States.”⁵⁶ Jones surmises that the resort to only male participants among the consulting doctors goes to “what every good clinician knows”:

[W]omen often fail to recognize the early symptoms of the disease because their genitals are largely internal and because the early symptoms are frequently mild and can easily be mistaken for unrelated problems involving vaginal itching and burning. By the time more severe symptoms develop and force them to seek medical care, women often learn to their dismay that the disease is well advanced. They also find it hard to pinpoint for their physicians when the early symptoms of the disease appeared, making it difficult to determine when the disease was contracted.⁵⁷

Although the all-white, all-male coalition purportedly made their decision on the basis of biology and irrefutable facts regarding the location of male/female genitalia, it should be noted that the first Rosenwald-type experiment accepted all ages of both sexes⁵⁸ and treated as many participants as the demonstration would accept.⁵⁹ Therefore, the Tuskegee Syphilis Study’s election to use all males should be reexamined in light of a historical representation of “[b]iomedical research [failing] to address the health needs of women”⁶⁰ by explicitly excluding all women in the protocol. It is imperative to acknowledge that the Black women of the Macon County, Alabama, both historically and presently, is unique in that Black women were excluded not only on the basis of gender, but also race, and such women have been generalized as part of a distinct race: the “notoriously syphilis soaked race.”⁶¹ Hence, the Black women directly

⁵⁵ *Id.* (noting that “an overview of the evolution of racial attitudes in American medicine is crucial to an understanding of the Tuskegee Study ... [beginning the discussion] in the nineteenth century, when the interaction between white physicians and Black patients produced what might be called ‘racial medicine’”).

⁵⁶ *Id.* at 103.

⁵⁷ *Id.* at 104.

⁵⁸ JOHNSON, *supra* note 23, at 188 (stating that “all ages of both sexes were examined”).

⁵⁹ *Id.*

⁶⁰ Vanessa Merton, *Ethical Obstacles to the Participation of Women in Biomedical Research*, in FEMINISM & BIOETHICS: BEYOND REPRODUCTION 216 (Susan M. Wolf, ed., 1996).

⁶¹ See Deleso Alford Washington, *Critical Race Feminist Bioethics: Telling Stories in Law School and Medical School in Pursuit of “Cultural Competency,”* 72 ALB. L. REV. 961, 964 (2009)

impacted by the effect of untreated syphilis were not deemed “worthy” of study.

The historical omission of the women directly impacted by the Tuskegee Syphilis Study speaks to Dorothy E. Roberts’ argument that “because women of color experience the intersection of gender and racial oppression, they may have unique critical insights to offer mainstream feminist theory and practice.”⁶² Knowledge of the historical marginalization of Black women in the Tuskegee Syphilis Study would aid future doctors and researchers in their decision-making when faced with the call regarding which sex to study.⁶³ The critical insight afforded to teaching medical students about the Tuskegee Syphilis Study lies in acknowledging the biomedical significance of overlooking the women directly impacted from the study, both in the past and today. Susan M. Wolf recognizes the Tuskegee Syphilis Study performed by the U.S. Public Health Service on [Blacks] amongst the foundational events contributing to the field of bioethics.⁶⁴ Hence, medical education can no longer afford not to study the Tuskegee Syphilis Study from a reproductive justice framework⁶⁵ (discussed in Section III in greater detail), which tells the “her-story”⁶⁶ of

[hereinafter Washington, *Critical Race Feminist Bioethics*] (stating that “[t]he reproductive and surgical exploitation meted upon three enslaved women, Anarcha, Betsey, and Lucy, among other un-named enslaved Black women, ‘othered’ their skin based upon a construction of ‘race,’ yet ‘samed’ their bodies for purposes of extracting reproductive knowledge, surgical inventions, and innovations to benefit all women”); see also JONES, *supra* note 3, at 27 (noting that “physicians reported that they saw and their estimates supported the general view that blacks had become, in the words of one doctor, a ‘notoriously syphilis-soaked race’”); WASHINGTON, *MEDICAL APARTHEID*, *supra* note 11, at 160 (explaining that “[t]he PHS castigated [Blacks] as a ‘notoriously syphilis-soaked race’”).

⁶² Dorothy E. Roberts, *Reconstructing the Patient: Starting with Women of Color*, in *FEMINISM & BIOETHICS: BEYOND REPRODUCTION* 117 (Susan M. Wolf ed., 1996) (noting that Roberts is not arguing that “women of color have a common or unique moral view point,” but that her concern is “primarily to identify how the perspective of poor women of color – their particular relationship to the institution of medicine – can uncover the way in which the practice of medicine, particularly the doctor-patient relationship, perpetuates hierarchies of power, can highlight women’s forms of resistance to medical control, and can propose a vision for transforming medical ethics and the health care system”).

⁶³ Merton, *supra* note 60, at 216 (arguing that “[t]he eligibility criteria in many scientific protocols explicitly bar some or all women. Other, apparently gender-neutral criteria in clinical trials in fact operate to exclude women. Biomedical research has concentrated on the investigation of health problems as they affect men—not surprisingly, largely explored in male research subjects. Until quite recently, bioethical analysis has failed to recognize and analyze the ethical issues inherent in this situation”).

⁶⁴ Susan Wolf, *Introduction: Gender and Feminism in Bioethics*, in *FEMINISM & BIOETHICS: BEYOND REPRODUCTION* 6 (Susan M. Wolf ed., 1996).

⁶⁵ Pamela D. Bridgewater, *Legal Stories and the Promise of Problematizing Reproductive Rights*, 21 *LAW & LIT.* 402, 411 (2009) (pointing out that the utilization of narrative or storytelling as a mode of inquiry in legal analysis will disturb the accepted discourse “and such disturbances are inherently valuable”).

⁶⁶ Deleso Alford Washington, “*Every Shut Eye Ain’t Sleep*”: *Exploring the Impact of Crack Cocaine Sentencing and the Illusion of Reproductive Rights for Black Women From a Critical Race Feminist Perspective*, 13 *AM. U. J. GENDER & SOC. POL’Y & L.* 123, 128-29 (2005) [hereinafter Washington, *Every Shut Eye*]. The “her-story” of the women of the Tuskegee Syphilis Study must be

the women of the Tuskegee Syphilis Study in order to adequately address the current accreditation mandate for cultural competency. Though the doctors did not believe that studying women was important and thus they were intentionally excluded, the women's experiences were indeed significant.

It should be noted that “[the] preoccupation with personal responsibility for disease assured syphilis a prominent place in the medical discussion of [B]lack health.”⁶⁷ The truth of the matter is that the microbe causing syphilis had been discovered by German researchers in 1905, and a therapy for treating the disease was later discovered in 1910.⁶⁸ Late nineteenth century physicians earnestly believed that they were on the eve of a discovery.⁶⁹ Nonetheless, the longest standing experiment with human subjects in medical history was executed in Macon County, Alabama to study the effect of *untreated* syphilis on negro males.⁷⁰ A brief overview of the disease,⁷¹ which was not being treated, follows:

The disease is caused by a type of bacterial organism named *Spirochaeta pallida*, or, more specifically, *Treponema pallidum*, a spirochete. Spirochetes are named for their spiral shape: Under a microscope, the wormlike bacteria wiggle furiously. *T. pallidum* can be acquired through sexual activity or congenitally, from an infected mother. In the initial stage of sexually transmitted syphilis, a chancre, or hard, painless sore, appears on the genitals or other point of entry, followed by flulike symptoms. If the disease is not treated, it enters a long latent secondary stage before emerging to

acknowledged for its historical omission and then critically examined for its biomedical significance. This work discussed the notion of ‘her-story’ in terms of: the Black woman’s story, which cannot be maintained in the background of history.

The Black woman’s body has known reproductive regulations and reproductive restraints. Her womb has been used as a reproductive resource center and as a receptacle or dumping ground for the sexual pleasure of those in power. The Black woman’s womb has been viewed as a contagion subjected to sterilization laws and abuses. Her womb has served and continues to serve as a discovery zone for the experimentation of contraceptives under the auspice of welfare reform or for the sake of advancing scientific knowledge. *Id.*

⁶⁷ JONES, *supra* note 3, at 22.

⁶⁸ *Id.* at 45. See EDWARD J. LARSON, SEX, RACE, AND SCIENCE : EUGENICS IN THE DEEP SOUTH 87 (1995) (noting that “[i]f syphilis could be properly diagnosed and effectively treated,’ as historian Alan Brandt observed about the resulting public health campaign, ‘then it could be placed on the same footing by boards of health as other contagious diseases”).

⁶⁹ JONES, *supra* note 3, at 22.

⁷⁰ Eunice Rivers, Stanley H. Schuman, Lloyd Simpson & Sidney Olansky, *Twenty Years of Followup Experience in a Long-Range Medical Study*, 68 PUB. HEALTH REP. 391 (1953) (pointing out that the Tuskegee study is one of the longest continuous studies of untreated syphilis), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2024316/pdf/pubhealthreporig00175-0085.pdf>

⁷¹ CHARLES S. JOHNSON, GROWING UP IN THE BLACK BELT: NEGRO YOUTH IN THE RURAL SOUTH, 234-35 (1941) (noting that “[o]nce a venereal disease is contracted, the probability of mortality is undoubtedly higher among rural Negroes than among any other groups”).

inflict an assortment of skin growths, running sores, gumma, bone decay, and heart damage. The final, tertiary, stage of syphilis may erupt several decades later, causing profound neurological damage—blindness, insanity (paresis), paralysis, and death.⁷²

This article calls for a critical examination of the devastation caused by the Tuskegee Syphilis Study to both males and females.

C. The Space: "The mere imparting of information is not education."
— Carter G. Woodson⁷³

The Tuskegee Syphilis Study reigns as the most infamous reminder of government-initiated unethical conduct meted upon human subjects. However, the prevailing issues of race, gender, and healthcare that have been historically under-discussed in a medical education setting are currently being mandated under the auspice of cultural competence.⁷⁴ Medical education provides a venue for an optimal understanding that "[c]ultural competence can be viewed in relation to general competence in professional medical practice as an integrated aspect of overall competence."⁷⁵ Pursuant to the Office of Minority Health:

In addition to defining cultural competence as essential to professional competence in general, cultural competence can be defined in terms of the power dynamics in medicine as well as society at large. The need for cultural competence arises from inherent power differential in the physician-patient relationship []. Ethnicity and social status are inextricably linked [], and social issues such as stereotyping, institutionalized racism, and dominant-group privilege are as real in the examining room as they are in society at large. Therefore, the goal of cultural competence training in health care should be to guide physicians in bringing these power imbalances into check. This process, consisting of ongoing self-reflection and self-critique, requires

⁷² WASHINGTON, MEDICAL APARTHEID, *supra* note 11, at 159.

⁷³ CARTER GODWIN WOODSON, *THE MIS-EDUCATION OF THE NEGRO* 20 (1933). Woodson, was an African-American historian, author, journalist and the founder of the Association for the Study of African American Life and History. He recognized and acted upon the importance of a people having an awareness and knowledge of their contributions to humanity and left behind an impressive legacy. A founder of *Journal of Negro History*, Dr. Woodson is known as the Father of Black History. See Corey Bowers Brown, *Carter G. Woodson*, <http://www.asalh.org/woodsonbio/sketch.html>.

⁷⁴ Margaret Montoya, *Defining the Voices of Critical Race Feminism: Defending the Future* *Voices of Critical Race Feminism*, 39 U.C. DAVIS L. REV. 1305, 1314; Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 993-95.

⁷⁵ See National Standards for Culturally and Linguistically Appropriate Services in Health Care, *supra* note 9, at 7.

humility.⁷⁶

“Today, as before, the Tuskegee Study has much to teach us about racism in the United States and the social warrant of medicine in people’s lives.”⁷⁷ The need to contextualize the purported “training” object of the Rosenwald/PHS alliance is wholly under-analyzed and would benefit from applying a notion of Critical Race Feminist Bioethics (“CRF Bioethics”).⁷⁸ The biomedical significance of the Tuskegee Syphilis Study becomes more apparent in light of the fact that “[t]he program’s medical services were designed to meet the Fund’s long-range goals. The demonstrations would provide training for “private physicians, white and colored, in the elements of venereal diseases treatments” and the “more extensive distribution of anti-syphilitic drugs and the promotion of wider use of State diagnostic laboratory facilities.”⁷⁹ Todd L. Savitt correctly points out that “[t]hroughout history medicine has required bodies for teaching purposes.”⁸⁰ The more introspective issue, however, is “whose body has the U.S. healthcare system historically exploited or marginalized due to the intersection of race, gender and research?” Medical schools should address this question as they train future doctors about the human toll in pursuit of medical research and training.

II. MEDICAL SCHOOL ACCREDITATION : PURPOSE AND VISION

...[T]he scientific blindspot to ethical issues that was responsible for the Tuskegee Study— what the [Atlanta] Constitution called “a moral astigmatism that saw these black sufferers simply as ‘subjects’ in a study, not as human beings.”⁸¹

Medical schools and graduate residency programs must meet minimum accreditation requirements including a cultural competency component.⁸²

⁷⁶ *Id.* at 8.

⁷⁷ JONES, *supra* note 3, at x.

⁷⁸ Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 998 (calling for an alternate approach to Bioethics, and asserting that “CRF Bioethics serves as a viable means to critically examine multiple perspectives which can begin to address the cultural competency goals medical schools are pursuing—to improve the quality and delivery of health care and address racial and ethnic disparities.”).

⁷⁹ JONES, *supra* note 3, at 59.

⁸⁰ Todd L. Savitt, *The Use of Blacks for Medical Experimentation and Demonstration in the Old South*, XLVIII J. S. HIST. 332, 332 (1982); Donald H. Rockwell, Anne Roof Yobs, & M. Brittain Moore, *The Tuskegee Study of Untreated Syphilis: The 30th Year of Observation*, 114 ARCHIVES OF INTERNAL MED. 792, 796 (1964) (noting that “[t]he Tuskegee Study has been very useful in evaluating serologic tests through the years”).

⁸¹ JONES, *supra* note 3, at 14.

⁸² AMERICAN COLLEGE OF PHYSICIANS, RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE,

Champaneria and Axtell note that:

Cultural perceptions of illness have been reported to influence health-seeking behaviors, patient-physician communication, and health outcomes. Recent changes in US demographics have underscored the demand for cultural awareness in clinical settings, as the current minority population in the United States is projected to exceed 50% by 2056. The percentage of minority physicians and medical students, however, has not been increasing proportionately. Medical schools have responded in part with 2 broad strategies: cultural immersion programs and cultural competence curricula. The former typically include either a clinical rotation in another country or a more local experience with native communities. In 2002, 38% of US medical students participated in international electives, compared with 6% in 1982. By contrast, cultural competence curricula use case-based, small-group formats to explore the core cultural issues and health beliefs of various ethnic groups, complementary and alternative medicine, language barriers, substance abuse, racism, and cross-cultural interviewing skills. Such curricula also include role play, panel discussions with patient advocates and interpreters, and simulated encounters.⁸³

Focus should be drawn to the significance of contextualizing the cultural competence curricula in order to satisfy accreditation mandates. Medical accreditation standards can serve as a tool to ensure that undergraduate and graduate medical education addresses salient issues surrounding the intersection of gender and race in the Tuskegee Syphilis Study, specifically via cultural competence curriculum content. William C. McGaghie notes that, "[t]he sad history of medicine's contribution to the legacy of racism in America from ignoring slavery to exclusionary medical school admission policies to the Tuskegee syphilis study scandal and beyond [is well documented]."⁸⁴

UPDATED 2010, 11 (2010) [hereinafter RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE]. The report surmises that:

The LCME (Liaison Committee on Medical Education) has issued an accreditation standard requiring all medical schools to incorporate cultural competence into their curricula. ACGME (Accreditation Council on Graduate Medical Education) has issued its own standards. The Association of American Medical Colleges has developed the Tool for Assessing Cultural Competence Training to assist medical schools in developing and integrating cultural competency content into school curriculum.

⁸³ See Manish C. Champaneria & Sara Axtell, *Cultural Competence Training in US Medical Schools*, 291 JAMA 2142 (2004).

⁸⁴ WILLIAM C. MCGAGHIE, MEDICAL EDUCATION FOR CULTURAL COMPETENCE: POLICIES, INITIATIVES, AND STUDENT SELECTION I (American Anthropological Association 2007).

Medical education's failure to teach about the biomedical significance of the Tuskegee Syphilis Study as it relates to the historical omission of women impacted by the study inherently impairs its ability to satisfy current cultural competence accreditation standards. The fact is, "[k]nowing the truth about our history will help to free us from the beliefs and attitudes about human differences that were deeply embedded in our culture with the invention of 'race' and 'races.'"⁸⁵ The process of accreditation is designed to promote quality assurance in postsecondary education.⁸⁶ It fosters institutional and program improvement.⁸⁷ The improvement of medical education through cultural competency mandates the acknowledgement of "the point of view of women of color bodies and experiences with interfacing with the healthcare system of the past and present."⁸⁸

A. Cultural Competence Accreditation Standards

The accreditation standards regulating medical education that are directly related to cultural competence both at the undergraduate and graduate levels are governed by the Liaison Committee on Medical Education (LCME) and Accreditation Council on Graduate Medical Education (ACGME), respectively. ⁸⁹ "Medical schools and graduate residency programs simply cannot operate if they fail to fulfill these minimum requirements."⁹⁰

a. The LCME

The LCME is a body composed of the American Medical Association (AMA) and AAMC that judges medical schools, including their curricula, facilities, and faculty, against a set of public standards.⁹¹ It is responsible for the accreditation of medical schools in the U.S. and Canada.⁹²

⁸⁵ AUDREY SMEDLEY, *THE HISTORY OF THE IDEA OF RACE . . . AND WHY IT MATTERS* 8 (American Anthropological Association 2007).

⁸⁶ See LIAISON COMMITTEE ON MEDICAL EDUCATION, *FUNCTIONS AND STRUCTURE OF A MEDICAL SCHOOL: STANDARDS FOR ACCREDITATION OF MEDICAL EDUCATION PROGRAMS LEADING TO THE M.D. DEGREE 1* (Liaison Committee on Medical Education 2010), available at <http://www.lcme.org> [hereinafter *FUNCTIONS AND STRUCTURE OF A MEDICAL SCHOOL*] (explaining the functions and structure a medical school must have/perform to be accredited).

⁸⁷ *Id.*

⁸⁸ Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 965.

⁸⁹ MCGAGHIE, *supra* note 84, at 2 (stating that for a medical school to be accredited it must meet the requirements of the LCME and ACGME).

⁹⁰ *Id.*

⁹¹ *Id.* at 3 (describing the functions and composition of the LCME).

⁹² *Id.*

Two measurable accreditation standards that U.S. and Canadian medical schools must fulfill to stay in operation, which are directly related to cultural competence and the undergraduate medical education minimum standards, are as follows:⁹³

ED-21. The faculty and students must demonstrate an understanding of the manner in which people of diverse cultures and belief systems perceive health and illness and respond to various symptoms, diseases, and treatments.⁹⁴

The LCME governing policy further explains ED-21:

Instruction in the medical education program should stress the need for medical students to be concerned with the total medical needs of their patients and the effects that social and cultural circumstances have on patients' health. To demonstrate compliance with this standard, the medical education program should be able to document objectives relating to the development of skills in cultural competence, indicate the location in the curriculum where medical students are exposed to such material, and demonstrate the extent to which the objectives are being achieved.⁹⁵

ED-22. Medical students . . . must learn to recognize and appropriately address gender and cultural biases in themselves, in others, and in the process of health care delivery.⁹⁶

The LCME governing policy further explains ED-22:

The objectives for instruction in the medical education program should include medical student understanding of demographic influences on health care quality and effectiveness (e.g., racial and ethnic disparities in the diagnosis and treatment of diseases). The objectives should also address the need for self-awareness among medical students regarding any personal biases in their approach to health care delivery.⁹⁷

Additionally, the LCME's mandate to provide students with instruction in medical ethics is embodied in ED-23: "A medical education program

⁹³ *Id.*

⁹⁴ See FUNCTIONS AND STRUCTURE OF A MEDICAL SCHOOL, *supra* note 86, at 10 (explaining that "ED" sections within the article are representative of the Educational Objectives set forth by the LCME).

⁹⁵ *Id.*

⁹⁶ *Id.* at 11.

⁹⁷ *Id.*

must include instruction in medical ethics and human values and require its medical students to exhibit scrupulous ethical principles in caring for patients and in relating to patients' families and to others involved in patient care."⁹⁸

Pursuant to ED-23:

The medical education program should ensure that medical students receive instruction in appropriate medical ethics, human values, and communication skills before engaging in patient care activities. As students take on increasingly more active roles in patient care during their progression through the curriculum, adherence to ethical principles should be observed, assessed, and reinforced through formal instructional efforts.

In medical student-patient interactions, there should be a means for identifying possible breaches of ethics in patient care, either through faculty or resident observation of the encounter, patient reporting, or some other appropriate method.

The phrase "scrupulous ethical principles" implies characteristics that include honesty, integrity, maintenance of confidentiality, and respect for patients, patients' families, other students, and other health professionals. The program's educational objectives may identify additional dimensions of ethical behavior to be exhibited in patient care settings.⁹⁹

b. The ACGME

The ACGME is the accrediting body responsible for the accreditation of post-MD medical training programs within the United States.¹⁰⁰ The accreditation process is governed by established standards and guidelines.¹⁰¹ Pursuant to the ACGME's by-laws, its purposes "are to develop the most effective methods to evaluate graduate medical education, to promote the quality of graduate medical education, and to deal with such other matters relating to graduate medical education as are appropriate."¹⁰²

In 1999, the ACGME endorsed competencies for all residents in the

⁹⁸ *Id.*

⁹⁹ *Id.*

¹⁰⁰ Accreditation Council for Graduate Medical Education, *available at* www.acgme.org.

¹⁰¹ *Id.*

¹⁰² Accreditation Council for Graduate Medical Education, *Bylaws* http://www.acgme.org/acWebsite/about/ab_ACGMEbylaws.pdf.

following six (6) areas:¹⁰³

- Patient Care
- Medical Knowledge
- Practice-based Learning and Improvement
- Interpersonal and Communication Skills
- Professionalism
- Systems-based Practice

It is mandatory that all programs integrate the general competencies into the curriculum. McGaghie notes that “[a]ll graduate medical education programs must be responsive to measurable cultural competence issues in at least two of the six areas.”¹⁰⁴ Pursuant to the ACGME’s Common Program Requirements: General Competencies:¹⁰⁵

i. Interpersonal and Communication Skills:

Residents must demonstrate interpersonal and communication skills that result in the effective exchange of information and collaboration with patients, their families, and health professionals. Residents are expected to:

- communicate effectively with patients, families, and the public, as appropriate, across a broad range of socioeconomic and cultural backgrounds;
- communicate effectively with physicians, other health professionals, and health related agencies;
- work effectively as a member or leader of a health care team or other professional group;
- act in a consultative role to other physicians and health professionals; and,
- maintain comprehensive, timely, and legible medical records, if applicable.

¹⁰³ Accreditation Council for Graduate Medical Education, *Common Program Requirements: General Competencies*, <http://www.acgme.org/outcome/comp/GeneralCompetenciesStandards21307.pdf>.

¹⁰⁴ MCGAGHIE, *supra* note 84, at 4.

¹⁰⁵ Accreditation Council for Graduate Medical Education, *Common Program Requirements: General Competencies*, <http://www.acgme.org/outcome/comp/GeneralCompetenciesStandards21307.pdf>.

ii. Professionalism:

Residents must demonstrate a commitment to carrying out professional responsibilities and an adherence to ethical principles. Residents are expected to demonstrate:

- compassion, integrity, and respect for others;
- responsiveness to patient needs that supersedes self-interest;
- respect for patient privacy and autonomy;
- accountability to patients, society and the profession; and,
- sensitivity and responsiveness to a diverse patient population, including but not limited to diversity in gender, age, culture, race, religion, disabilities, and sexual orientation.

A major difference between undergraduate and graduate medical education is that the latter generally operates “under auspices of hospitals and academic medical centers affiliated with medical schools and is usually not managed by the schools themselves.”¹⁰⁶

“In graduate medical education, residents are both students and doctors,”¹⁰⁷ thereby further promoting the need for a culturally competent medical education due to the direct physician- patient interaction and the promotion of trust for the healthcare system. Pursuant to the Report on Racial and Ethnic Disparities in Health Care, Updated 2010:

Evidence that cultural competency training can lead to improved patient outcomes and fewer liability claims exists, although more research is needed. To understand and treat racial and ethnic minorities better, physicians must engage in cultural competency training at all medical education levels. An increasing number of medical schools offer pathways to cultural competence development, but more needs to be done.¹⁰⁸

Both the undergraduate and graduate medical accreditation standards

¹⁰⁶ MCGAGHIE, *supra* note 84, at 4.

¹⁰⁷ Michael J. Frank, *Safeguarding The Consciences of Hospitals and Health Care Personnel: How The Graduate Medical Education Guidelines Demonstrate a Continued Need for Protective Jurisprudence and Legislation*, 41 ST. LOUIS U. L.J. 311, 316 (1996).

¹⁰⁸ RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE, *supra* note 82, at 11.

relating to cultural competency are designed to ultimately address existing health care disparities.¹⁰⁹

III. REPRODUCTIVE JUSTICE LENS FOR A TRANSFORMATIVE REMEDY

*“When you [see] better, you [teach] better.”*¹¹⁰

Medical education should address the Tuskegee Syphilis Study’s “blind spot”¹¹¹ by also acknowledging the women who were directly impacted by the Study. Robby Reynolds, MPA, Director of MedEd PORTAL & CurrMit points out, “[m]edical schools need tools and resources beyond a curriculum management system in the areas of Evaluation, Curriculum Content Delivery and Scheduling.”¹¹² The Tuskegee Syphilis Study’s biomedical significance to women is not adequately addressed in medical schools. It is essential that a reproductive justice framework be implemented to assist in the development of culturally competent curricula, as it relates to the Tuskegee Syphilis Study’s impact on women. A transformative remedy would acknowledge the problem relating to distrust of the public health care system amongst Black people generally, and Black

¹⁰⁹ *Id.* at 1 (noting that “[i]ncreased interest and validation of the importance of cultural competence by the medical community is encouraging. Better understanding between those of different cultures and primary languages is critical to closing the health disparities gap and improving care”).

¹¹⁰ Author’s poetic privilege on teaching cultural competence infused with Critical Race Feminist (CRF) theory. See *John* 9:25 (King James) “...I was blind, now I see.” And Grandmother Gertrude’s saying, “When you [know] better, you do better.” See Montoya, *supra* note 74, at 1318 (stating that “CRF has a tremendous contribution to make in this area of cultural and linguistic competence”); see also Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 982-83 (arguing that “[t]he lens of CRF compels the storyteller [medical schools] to not only speak about ‘unspeakable’ things, such as notions of race and racial construction, gender, and locations of power in the health care system – it also encourages the [medical students] to hear the silence of issues raised but not adequately addressed”).

¹¹¹ W. MICHAEL BYRD & LINDA A. CLAYTON, AN AMERICAN HEALTH DILEMMA: A MEDICAL HISTORY OF AFRICAN AMERICANS AND THE PROBLEM OF RACE: BEGINNINGS TO 1900 24 (2000) [hereinafter BYRD & CLAYTON, A MEDICAL HISTORY] (citing “James H. Jones’s impression that the U.S. medical profession, and the biomedical research establishment that it has erected over the past century, has a ‘blind spot’ when it comes to understanding the detrimental effects its racial attitudes and practices have on Black patients and national health policy”).

¹¹² The Association of American Medical Colleges (AAMC) Annual Meeting (Washington, D.C., Nov. 9, 2010), Central Management of the Curriculum: Different Approaches, Different Challenges, available at https://www.aamc.org/about/annual_report/ The AAMC’s mission is to serve and lead the academic medicine community to improve the health of all. It represents all 133 accredited U.S. and 17 accredited Canadian medical schools. The vision of the AAMC and its members is a healthy nation and world in which: America’s system of medical education, through continual renewal and innovation, prepares physicians and scientists to meet the nation’s evolving health needs; the nation’s medical students, biomedical graduate students, residents, fellows, faculty, and the health care workforce are diverse and culturally competent; advances in medical knowledge, therapies, and technologies prevent disease, alleviate suffering, and improve quality of life; and the nation’s health system meets the needs of all. Association of American Medical Colleges, *About*, <http://www.aamc.org/about/>

women specifically. There are several critical teaching tools for reexamining the Tuskegee Syphilis Study.

A. Reproductive Justice Lens

According to Bernadine Healy, M.D., former Director of the National Institutes of Health, “[b]eing different from men [has] meant being second-class and less than equal for most of recorded time and throughout most of the world.”¹¹³ Adding to Healy’s observation, a reproductive justice framework is needed to acknowledge yet another degree of “second-class” citizenry: when the difference occupies the body of a woman subordinated within “intersecting oppressions of race, class, gender, sexuality, and nation.”¹¹⁴ According to the SisterSong Women of Color Reproductive Justice Collective:¹¹⁵

Reproductive Justice is a base-building analysis that focuses on organizing women, girls and their communities to challenge structural power inequalities in a comprehensive and transformative process of empowerment. The Reproductive Justice analysis offers a compelling and more defensible framework for empowering women and girls and is relevant to every American family.¹¹⁶

The utilization of a reproductive justice lens in medical schools to achieve cultural competency accreditation standards necessitates going beyond “asking the women question,”¹¹⁷ particularly when critically analyzing a facially neutral issue such as the selection of research subjects. The aspect of reproductive justice that challenges structural inequality would require one to reframe the “asking the woman question” to the “asking the woman

¹¹³ Merton, *supra* note 60, at 261 (citing Bernadine Healy, *The Yentl Syndrome*, NEW ENG. J. OF MED. 325 (1991)).

¹¹⁴ PATRICIA HILL COLLINS, *BLACK FEMINIST THOUGHT: KNOWLEDGE, CONSCIOUSNESS AND THE POLITICS OF EMPOWERMENT* (2d ed. 2000) (pointing out that, “[a]s long as Black women’s subordination within intersecting oppressions of race, class, gender, sexuality, and nation persists, Black feminism as an activist response to that oppression will remain needed”).

¹¹⁵ See <http://www.sistersong.net/herstory.html>. The SisterSong Women of Color Reproductive Justice Collective is a network of local, regional and national grassroots agencies representing five primary ethnic populations/indigenous nations in the United States: African American, Arab American/Middle Eastern, Asian/Pacific Islander, Latina and Native American/Indigenous.

¹¹⁶ Loretta J. Ross, *Understanding Reproductive Justice*, (2006) available at http://www.sistersong.net/publications_and_articles/Understanding_RJ.pdf.

¹¹⁷ Wolf, *supra* note 64, at 8 (Susan M. Wolf ed., 1996) (defining “feminism” and its offshoot “feminist work,” and pointing out that merely paying attention to the category of “women,” as important as it is, does not make work feminist. One can attend to the category yet abstain from analyzing and challenging oppression. There is a difference between asking the “women question” – Where are the women in this picture? – and going on to perform feminist analysis.).

of color question,"¹¹⁸ so as to acknowledge gender, race, and class disparities in healthcare generally, as well as research specifically. Applying a reproductive justice framework to the recounting of the Tuskegee Syphilis Study – historically as well contemporarily – calls for a critique of women and research.

Vanessa Merton argues:

For too long, gender has substituted for more precise biological attributes to achieve and illusory "homogeneity" that serves certain research goals at the expense of others. From a \ woman's point of view, this model of research has not been more efficient. Efficiency requires definition of a desired endpoint and assessment of the extent of its achievement. For women, the desired endpoint of biomedical research-knowledge useable by and useful for the entire universe of people, including the pregnant and potentially pregnant woman- had not been achieved to any satisfactory degree.¹¹⁹

Exploring the "asking the woman of color question" when examining the Tuskegee Syphilis Study yields great insight into present day omissions of research involving women.¹²⁰ According to the reports from the initial meetings on framing the protocol for the Tuskegee Syphilis Study, females were not selected "because it [would be] next to impossible to get reliable information as to the date of infection of syphilis in the female."¹²¹ Simply put, the women were excluded from the purported "research" by virtue of their different physiological makeup, although both women and children were included as participants in the earlier Rosenwald Demonstrations.¹²² The truth of the matter conceivably lies in the decision to take advantage of the Rosenwald Demonstrations' goodwill to secure participants for a study on the effects on *untreated* syphilis, while misleading them to believe that they were in fact receiving treatment.¹²³ Gray points out that "[f]ield hands

¹¹⁸ Judy Scales-Trent, *Women of Color and Health: Issues of Gender, Community, and Power*, 43 STAN. L. REV. 1357, 1364 (1991) (examining the "women of color issue" through the context of health issues, and contending that "[t]he term 'women of color' can be a helpful political tool. It is a phrase which is affirming and generous, a phrase which brings together a powerful coalition of women.").

¹¹⁹ Merton, *supra* note 60, at 225.

¹²⁰ Scales-Trent, *supra* note 118, at 1362 (pointing out the lack of adequate medical or social science research on the health issues of women of color, and that medical research has a strong inclination to focus on the health issues of men).

¹²¹ JONES, *supra* note 3, at 104 (This is pursuant to Dr. Talifero Clark's notes of the meeting with experts, including an association of medical researchers and distinguished syphilologists in the United States (the Cooperative Clinical Group). *Id.* at 103.

¹²² JOHNSON, *supra* note 23 at 188.

¹²³ RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* 165 (1986) (stating that "a loss of funding led PHS physicians to shift their focus from treatment to mere

and manual workers were sought out by Vonderleher so that he would not have to waste his Wasserman [sic] tests on women.”¹²⁴ The Wassermann test, generally speaking, refers to a series of blood tests that the government doctors administered to diagnose syphilis and assess its progress.¹²⁵

To date, “[b]iomedical research has concentrated on the investigation of health problems as they affect men – not surprisingly, largely explored in male research subjects. Until quite recently, bioethical analysis has failed to recognize and analyze the ethical issues inherent in this situation.”¹²⁶ The inclination to overlook women in research is necessary to maintain a status quo of “second-class citizenry” healthcare, thereby resulting in unethical conduct. Even in light of “[s]candals such as the Tuskegee Syphilis Trials [which] motivated efforts to protect research subjects by excluding them from research”¹²⁷ based upon a lack of informed consent, the current discourse on the Tuskegee Syphilis Study fails to “ask the women of color question” and its implications for women and research today. As Merton points out, “[a]lmost nowhere in the massive bioethical literature on experimentation is there any reference to a right to be considered for a research protocol, or to a corresponding duty to avoid unjustly or irrationally excluding those who might wish to be subjects.”¹²⁸

The omission of women from the protocol in the Tuskegee Syphilis Study in 1932 foreshadows the medical “her-story” of marginalization that currently exists. It has been argued that “medical and other health care practices should be reviewed not just with regard to their effects on the patients who are directly involved but also with respect to the patterns of discrimination, exploitation, and dominance that surround them.”¹²⁹ This is especially true in the Tuskegee Syphilis Study, due to the known effects of the disease, which can be acquired through sexual activity or congenitally from an infected mother.¹³⁰

A reproductive justice lens will allow one to acknowledge the

observation”); Stephen B. Thomas & Sandra Crouse Quinn, *The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community*, 81 AM. J. PUB. HEALTH 1498, 1499 (1991) (opining that “the start of the Depression in 1929 devastated the Rosenwald Fund’s financial resources, which were needed for the treatment component of the demonstration project. Without financial support from the Rosenwald Fund, the PHS simply did not have the resources to develop treatment programs in all five counties. It was thought that the best chance of salvaging anything of value from the project lay in the conduct of a scientific experiment.”).

¹²⁴ GRAY, *supra* note 4, at 96.

¹²⁵ JONES, *supra* note 3, at 45.

¹²⁶ Merton, *supra* note 60, at 216.

¹²⁷ *Id.* at 217.

¹²⁸ *Id.*

¹²⁹ *Id.* quoting Susan Sherwin.

¹³⁰ WASHINGTON, MEDICAL APARTHEID, *supra* note 11, at 159.

biomedical significance of the Tuskegee Syphilis Study to current issues of omitting women in research protocols. According to Lorretta Ross, National Coordinator, SisterSong Women of Color Reproductive Health Collective, the development of the term "Reproductive Justice" evolved from a definition of:

"reproductive health integrated into social justice." Reproductive justice, at that time, was defined as "reproductive health integrated into social justice." Reproductive justice was further developed as an intersectional theory emerging from the experiences of women of color whose communities experience reproductive oppression. It is based on the understanding that the impact on women of color of race, class and gender are not additive but integrative, producing this paradigm of intersectionality. The concept of reproductive justice was further elaborated in a seminal paper written by Asian Communities for Reproductive Justice in 2005. ACRJ strengthened the Reproductive Justice analysis by analyzing the three main frameworks for fighting reproductive oppression: 1) Reproductive Health which deals with service delivery, 2) Reproductive Rights which address the legal regime, and 3) Reproductive Justice which focuses on movement building.¹³¹

By applying a reproductive justice lens to a reexamination of the Tuskegee Syphilis Study, one ascertains that the government denied the women directly impacted by the study the right to not bear a child with congenital syphilis, because of the government doctors' intention to study the effect of *untreated* syphilis on men (the husbands and intimate partners of the women who contracted syphilis) and, unbeknownst to them, passed the disease on to their unborn children.

The reproductive justice lens lays the foundation for a transformative remedy to address African American distrust of the public health care system. The transformative nature of medicine and provision of medical services will be manifested when medical schools reframe the discussion of the women affected by the Tuskegee Syphilis Study as mere collateral consequences to the center of discourse when teaching the biomedical significance of women. By de-marginalizing the presence and narrative of women of color in medical research, medical schools will meet their

¹³¹ Ross, *supra* note 116, at 1. Legal scholarship interpreting the concept of "intersectionality" are voluminous. See, e.g., Kimberle Crenshaw, *Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color*, 43 STAN. L. REV. 1241, 1279 (1991).

mandates of incorporating a culturally competent curriculum, which will undoubtedly transform the field of medicine, medical research, and the provision of medical services.

B. Transformative Remedy

In order to fully appreciate the necessity of a transformative remedy, one must first recognize a form of injustice. Arguably, the accreditation mandates for cultural competence in medical education, continued discussions, and generated research amongst medical and legal professionals in or concerned with the healthcare field, are indicative of efforts to acknowledge existing injustices manifested by disparities in health care.¹³² A transformative remedy can be implemented to address medical education's cultural competence accreditation standards, by exploring the roots of the most infamous government initiated biomedical ethical abuse in U.S. medical history with a reproductive justice lens.

The notion of a "transformative remedy" should be explored from Nancy Fraser's working definition, wherein she compares alternative remedies of injustice by distinguishing between "affirmative remedies" and "transformative remedies."¹³³ Fraser explains that affirmative remedies target end-state outcomes and transformative remedies address root causes.¹³⁴ The historical and present day omission of the biomedical significance of the Tuskegee Syphilis Study to women and research calls for a just remedy. To achieve this result, one must examine both traditionally-exposed root causes, as well as historically-unexposed root causes for the negative aftermath of the Tuskegee Syphilis Study.

C. Tuskegee Syphilis Study and Distrust: Root Causes In Context

As Professor Vernellia Randall explains, "fear and distrust of the health care system is a natural and logical response to the history of experimentation and abuse. The fear and distrust shape our lives and, consequently, our perspectives."¹³⁵ It is critical to examine the root causes for the existence of distrust amongst African Americans and the public

¹³² Marek Hrubec, *Towards Global Justice: An Interview with Nancy Fraser*, 40 CZECH SOC. REV. 879, 880 (2004).

¹³³ *Id.*

¹³⁴ *Id.*

¹³⁵ Vernellia R. Randall, *Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy! An African American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191, 191 (1996).

health care system. The Tuskegee Syphilis Study is oftentimes the most cited reason for such distrust.¹³⁶ Although the Tuskegee Syphilis Study is framed as the longest government initiated ethical abuse meted against Blacks, one cannot overlook the legacy of U.S. Slavery¹³⁷ and the legal fiction of chattel property that allowed people of African descent to be bought, sold, and used for medical experimentation.¹³⁸ Within the historical context, the Tuskegee Syphilis Study is one incidence that perhaps further solidified the level of distrust amongst Blacks and the healthcare system, but certainly it is not the sole reason.¹³⁹ It is perhaps the depth of the misleading nature of a government sanctioned medical experiment during modern times that is most bothersome to some.¹⁴⁰ Faden and Beauchamp note as amongst the egregious facts regarding the Tuskegee Syphilis Study:

These subjects knew neither the name nor the nature of their disease. That they were participants in a non-therapeutic experiment also went undisclosed. They were informed only that they were receiving free treatment for "bad blood," a term local blacks associated with a host of unrelated ailments, but which the white physicians allegedly assumed was a local euphemism for syphilis. No attempt was made to explain what "bad blood" meant, presumably because the physicians believed that the subjects were incapable of comprehending any complex explanation. The investigators assumed that the subjects would comply without question; their deference to authority and desire to receive medical attention made them

¹³⁶ Stephen B. Thomas & Sandra Crouse Quinn, *The AIDS Epidemic and the African-American Community: Toward an Ethical Framework for Service Delivery*, in *IT JUST AIN'T FAIR: THE ETHICS OF HEALTH CARE FOR AFRICAN AMERICANS* 83 (Annette Dula & Sara Goering eds., 1994) (arguing that "the legacy of [the Tuskegee Syphilis] experiment, with its failure to educate the study participants and treat them adequately, laid the foundation for today's pervasive sense of black distrust of public health authorities").

¹³⁷ BYRD & CLAYTON, *A MEDICAL HISTORY*, *supra* note 111, at 245 (positing that: "[I]n an American health system already dividing along class lines, with a stringent if not draconian moral perspective plagued by pervasive race and slavery problems, negotiating such a system was incredibly difficult for Blacks, whether slave or free. African Americans were not only burdened with the stigma of low socioeconomic status and 'unworthiness,' but they also underwent health system abuse, exploitation, segregation, and discrimination on the basis of their race.").

¹³⁸ See Savitt, *supra* note 80 (noting that an abundance of sources reveal that "slaves had a fairly significant role in medical education" in the South).

¹³⁹ Randall, *supra* note 135, at 200 (detailing specific examples of experimentation during slavery, post-slavery, prison, and military service of abuse meted against Black people. "While many Blacks may not be able to give you the details of the experimentation and abuse, the instances are a part of the collective Black consciousness which still influence African Americans' reaction to the health care system.").

¹⁴⁰ *Id.* at 197-98 (highlighting that the medical establishment was complicit in its silence from 1932 through 1972, during the course of the Tuskegee Syphilis Experiment, despite medical journal reports publishing the findings. "The Tuskegee study served to reinforce the belief in the African American community that the distrust of the medical system was not merely an historical issue.").

readily available subjects. The subjects were also misinformed that research procedures such as painful spinal taps were a “special free treatment,” a patently false statement. As historians James Jones and David Rothman have both argued, theirs was a “manipulated consent”, extracted from subjects in such “social deprivation” that manipulation came effortlessly.¹⁴¹

This type of callousness and disregard for humanity engenders a well-founded predisposition within the African American community to distrust public health initiatives, which should be emphasized when teaching the Tuskegee Syphilis Study. The recognition of a present day shadow of distrust that lingers over the healthcare system and its interactions with people of color generally, and Black people specifically, arguably served as an impetus to campaign for a Presidential Apology for the Tuskegee Syphilis Study.¹⁴² President William Clinton stated in the presence of surviving participants and their families:

No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry.¹⁴³

The 1997 Presidential apology was significant, but ultimately insufficient to quiet Black distrust of the healthcare system and the inclination to link the Tuskegee Syphilis Study as support for reluctance to participate in clinical research trials, such as HIV/AIDS prevention and treatment

¹⁴¹ See FADEN & BEAUCHAMP, *supra* note 123, at 165; see also Brandt, *Racism and Research*, *supra* note 15, at 21-22 (“Further difficulties arose in enlisting the subjects to participate in the experiment, to ‘Wassermanned,’ and to return for a subsequent series of examinations, Vonderlehr found that only the offer of treatment elicited the cooperation of the men. They were told they were ill and were promised free care. Offered therapy, they became willing subjects. The USPHS did not tell the men they were participants in an experiment; on the contrary, the subjects believed they were being treated for ‘bad blood’ – the rural South’s colloquialism for syphilis. They thought they were participating in a public health demonstration similar to the one that had been conducted by the Julius Rosenwald Fund in Tuskegee several years earlier. In the end, the men were so eager for medical care that the number of defaulters in the experiment proved to be insignificant.”).

¹⁴² See Vanessa Northington Gamble, *Under the Shadow of Tuskegee: African Americans and Health Care*, 87 AM. J. PUB. HEALTH 1773 (1997) (discussing how “[n]umerous articles, in both the professional and popular press, have pointed out that the study predisposed many African Americans to distrust medical and public health authorities and has led to critically low Black participation in clinical trials and organ donation”); see also GRAY, *supra* note 4, at 114-32 (providing a detailed background account of the historical Presidential apology that took place at the White House on May 16, 1997).

¹⁴³ GRAY, *supra* note 4, at 114-15.

programs.¹⁴⁴ Gamble notes that “[t]he syphilis study has also been used to explain why many African Americans oppose needle exchange programs.”¹⁴⁵ The reasons for the present day distrust are no less valid in the collective memory of Black people than any opposing views of its absurdity. However, a critical examination of the historical relationship between Blacks and the health care system reveals that the Tuskegee Syphilis Study must be viewed within a broader historical and social context.¹⁴⁶ Moreover, utilizing a reproductive justice lens enhances the understanding of the general attitudes about medical research held by African Americans, as well as a means to address them.

D. Tuskegee Syphilis Study and Distrust Amongst African American Women: Traditionally Unexposed Root Causes

The life experiences of Black women and health care often present intersecting issues involving reproductive health.¹⁴⁷ The Black woman’s particularized experience is traditionally marginalized, but nonetheless deeply seeded in distrust, which is both historically based and existent in contemporary instances of medical research. A historical account of the Black woman being “studied” is the ‘her-story’ of Saartjie Baartman, a Black South African Khoi-San woman often referred to as the “Hottentot Venus.”¹⁴⁸ George Cuvier, known as the “Father of Paleontology and Comparative Anatomy,” dissected her body at an autopsy and published his “scientific findings:” a “document [of] monkey-like” racial differences that fortified beliefs of Black inferiority for more than a century.¹⁴⁹ Another historical her-story occurred at the hands of Dr. J. Marion Sims, who was known as the “Father of Gynecology;” Dr. Sims appropriated the Black woman’s body as a reservoir for scientific knowledge in order to discover a cure for “vesico-vaginal fistula,” a medical condition involving internal

¹⁴⁴ See generally Thomas & Quinn, *supra* note 123, at 1498-1505 (“The history of the Tuskegee Syphilis Study, with its failure to educate the participants and treat them adequately, helped to lay the foundation for Blacks’ pervasive sense of distrust of public health authorities today.”).

¹⁴⁵ Gamble, *supra* note 142, at 1773.

¹⁴⁶ *Id.* (“An examination of the syphilis study within a broader historical and social context makes plain that several factors have influenced, and continue to influence, African Americans’ attitudes toward the biomedical community.”).

¹⁴⁷ Lisa C. Ikemoto, *In The Shadow of Race: Women of Color in Health Disparities Policy*, 39 U.C. DAVIS L. REV. 1023, 1025 (2006) (Framing the issue this way: “[i]n the context of health care, the core failure – inattention to the intersections of categories used for social ordering – leaves the particular ways that racialized patriarchy allocates health risks to women of color out of sight and out of mind.”).

¹⁴⁸ BYRD & CLAYTON, A MEDICAL HISTORY, *supra* note 111, at 217.

¹⁴⁹ *Id.*

tears in the vaginal wall leading to urinary and sometimes fetal incontinence, most often caused during traumatic childbirth.¹⁵⁰ The ‘her-story’ of Anarcha, Betsey, Lucy and other un-named enslaved Black women lay at the intersection of race, gender, and reproductive health, resulting in the development of the specialty of gynecology in the United States.¹⁵¹ As to the Tuskegee Syphilis Study and distrust amongst Black women, a reproductive justice lens would bring to focus the inherent structural inequality of the selective construction of Black women’s bodies at the behest of scientific goals, whether “raced” or “gendered” depending on the end-state outcome – or as Fraser refers to it, the “affirmative remedy.”¹⁵²

For instance, Cuvier’s dissection of Saartjie Baartman’s “raced” body ultimately resulted in findings which supplied the “scientific” affirmation of the natural inferiority of Blacks. In comparison, Sims’ unanesthetized experiments on the “gendered” bodies of Anarcha, Betsey, and Lucy ultimately resulted in medical technologies and surgical instruments that benefited all women, both then and now.. However, the Tuskegee Syphilis Study reflects the selectivity of white governmental doctors’ decisions to exclude all females in the research protocol with respect to a venereal disease that impacted both males and females. Even though race situated the Tuskegee women in the so-called “notoriously syphilis soaked race,”¹⁵³ her gender deemed her an “unworthy” human subject. A reproductive justice lens clarifies the reality that Nurse Rivers was “powerless to advocate for the wives of the men [in the study] who asked why only men could be in the study.” “‘We’re sick too, Nurse Rivers,’” they said.”¹⁵⁴ It is the axis of historical and social context that accounts for feelings of distrust among African American women and the healthcare system; and this axis makes structural inequality evident. Recent research indicates that:

Distrust of the white dominated medical community either because of Tuskegee or the long history of the subordination of black people in [a given] community at the hands of whites,

¹⁵⁰ See generally Barbara L. Bernier, *Class, Race, and Poverty: Medical Technologies and Socio-Political Choices*, 11 HARV. BLACKLETTER L. J. 115, 118 (1994) (discussing accounts of Sims’ use of Alabama slave women for medical experimentation); Camille A. Nelson, *American Husbandry: Legal Norms Impacting The Production of (Re)Productivity*, 19 YALE J.L. & FEMINISM 1, 4 (2007); Randall, *supra* note 135, at 197.

¹⁵¹ Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 983-83 (providing a detailed account of the over-looked narratives of Anarcha, Betsey, and Lucy as integral to the development of the specialty of gynecology).

¹⁵² Hrubek, *supra* note 132, at 880.

¹⁵³ WASHINGTON, MEDICAL APARTHEID, *supra* note 11, at 157.

¹⁵⁴ Hammonds, *supra* note 8, at 341.

obviously plays some role in the reluctance of blacks to participate in clinical research. In the black community suspicions linger about the real goals of medical research—especially when the research involves genetic screening.¹⁵⁵

Even though the poor representation of Black women in medically oriented research is well-documented, the reasons for the low participation do not solely rely on the exploitation and abuse of the Tuskegee Syphilis Study.¹⁵⁶ In order to locate equitable research, a reproductive justice lens would train one to “make research participation more meaningful to people from differing backgrounds and improve research methodologies to be inclusive for all segments of the population.”¹⁵⁷ The utilization of a reproductive justice lens will aid in the establishment of a transformative remedy to teach about the impact of the Tuskegee Syphilis Study, by addressing both traditionally exposed and unexposed roots of injustice concerning Black women and research.

IV. RECOMMENDATION FOR CULTURALLY COMPETENT CURRICULA DELIVERY: THE TUSKEGEE SYPHILIS STUDY

Medical education’s culturally competent accreditation standards present a need for curricular content delivery.¹⁵⁸ The Agency for Healthcare Research and Quality notes that “[c]ultural competency training can be achieved by infusion, integrating a multicultural perspective throughout curriculum or training activities.”¹⁵⁹ This idea of infusion of perspectives

¹⁵⁵ *The Reluctance of Black People to Participate in Clinical Medical Research*, 17 J. OF BLACKS IN HIGHER EDUC. 33, 33-34 (1997); Giselle Corbie-Smith, Stephen B. Thomas, Mark V. Williams & Sandra Moody-Ayers, *Attitudes and Beliefs of African Americans Toward Participation in Medical Research*, 14 J. GEN. INTERN. MED. 537, 537 (1999) (concluding that “African-American participants in [the] study described distrust of the medical community as a prominent barrier to participation in clinical research”).

¹⁵⁶ Tovia G. Freedman, “*Why Don’t They Come to Pike Street and Ask Us?*”: *Black American Women’s Health Concerns*, 47 SOC. SCI. & MED. 941, 941 (1998).

¹⁵⁷ *Id.* at 946.

¹⁵⁸ See *supra* note 117 (recounting one author’s observations regarding the U.S. medical profession’s failure to recognize the negative effects of racial attitudes and practices, and the related impact on patients of color and health policy nationally); see also Susan J. Landers, *Mandating Cultural Competency: Should Physicians be Required to Take Courses?*, AM. MED. NEWS, Oct. 19, 2009, available at <http://www.ama-assn.org/amednews/2009/10/19/prsa1019.htm> (noting that mandatory cultural competency training for physicians is gaining momentum); Robert C. Like, Theresa J. Barrett & Jeffrey Moon, *Educating Physicians to Provide Culturally Competent, Patient-Centered Care*, Summer 2008 PERSPECTIVES 10., available at <http://www.acofp.org/education/LV10/handouts/Sat32009/LikeRobertCulturalCompetencyaddtlhandouts/NJAFPCompressedEducatingPhysiciansCulturalCompetency.pdf> (observing that in 2005, “New Jersey lawmakers enacted legislation” that all physicians complete cultural competency training as a condition of their “relicensure”).

¹⁵⁹ Cindy Brach & Irene Fraserirector, *Can Cultural Competency Reduce Racial and Ethnic*

into the medical curriculum is echoed in Professor Margaret Montoya's call for the "[t]he fusion of [Critical Race Feminist Theory] CRF from law schools with linguistic and cultural competence from medical schools."¹⁶⁰ This Article contends that CRF offers critical teaching tools necessary to enhance culturally competent curricular content for medical schools. The focus of this section is to provide an example of "CRF Teaching Points," particularly as to the use of deconstructive techniques and narratives. Part A will introduce critical teaching tools. Part B will demonstrate deconstructive techniques to teach about the Tuskegee Syphilis Study through the contemporary lens of the HBO movie, *Miss Evers Boys*. Part C will explore the use of narrative by examining "her-story," the unique and particularized experiences of Black women which would otherwise be marginalized. "Scientific investigators had to learn that 'moral judgment should always be a part of any human endeavor,' including 'the dispassionate scientific search for knowledge.'¹⁶¹ Accordingly, medical students should learn this invaluable lesson as a part of the mandate for a culturally competent education. This final section examines critical teaching tools to recount the Tuskegee Syphilis Study and its biomedical significance on women and research, in order to begin to assist medical schools in their mandate to demonstrate minimum proficiency in the area of cultural competency for purposes of accreditation.

A. Critical Teaching Tools for the Infusion of CRF into Medical School Curriculum

The infusion of CRF theory as a means to ensure cultural competent curricular in medical schools has been advanced.¹⁶² "[C]ritical race feminists provide the tools for challenging subordination at its core and understanding how various oppressions are connected and interrelated – setting the stage for truly transformative change in our society."¹⁶³ This

Health Disparities? A Review and Conceptual Model, 57 MED. CARE RESEARCH & REV. 181, 186 (SUPPLEMENT 1, 2000) (indicating that cultural competency can be achieved by including a "multicultural perspective" in training and curricula).

¹⁶⁰ Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 969 (citing Montoya, *supra* note 74, at 1314) (concluding that there would be value in a combination of "CRF from law schools with linguistic and cultural competence from medical schools").

¹⁶¹ JONES, *supra* note 3, at 14 (commenting on the need for "moral judgment" in the context of scientific research and innovation).

¹⁶² See Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 969 (citing Montoya, *supra* note 74, at 1314) (proposing a union of the CRF principles that have become more prevalent in law schools with the "linguistic and cultural competenc[ies]" that are already pervasive in medical schools).

¹⁶³ Angela Onwuachi-Willig, *This Bridge Called Our Backs: An Introduction to "The Future of*

section will examine basic tenets of CRF theory and their effectiveness toward assisting medical schools to satisfy culturally competent mandatory accreditation standards. CRF traditionally "draws from critical legal studies the idea of deconstruction along with the critical analysis of the traditional legal canon."¹⁶⁴ J.M. Balkin argues that:

Lawyers should be interested in deconstructive techniques for at least three reasons. First, deconstruction provides a method for critiquing existing legal doctrines; in particular, a deconstructive reading can show how arguments offered to support a particular rule undermine themselves, and instead, support an opposite rule. Second, deconstructive techniques can show how doctrinal arguments are informed by and disguise ideological thinking. This can be of value not only to the lawyer who seeks to reform existing institutions, but also to the legal philosopher and the legal historian. Third, deconstructive techniques offer both a new kind of interpretive strategy and a critique of conventional interpretations of legal texts.¹⁶⁵

I contend that medical school curricula will move toward satisfying cultural competence mandates through critical teaching tools, such as deconstructive techniques as employed by CRF theory. Professor Adrien Wing asserts that critical race feminism draws from critical legal studies the idea of deconstruction along with the critical analysis of the traditional legal canon.¹⁶⁶

An example of deconstructive inquiry can be gleaned from some key Critical Race Theory or CRF components set forth by Margaret Montoya:

- a. The role that science has played and continues to play in constructing racial identities, and the concepts we understand as "race" or "racialized ethnicities."
- b. How law has created and sustained white supremacy.

Critical Race Feminism, 39 U.C. DAVIS L. REV. 733, 736 (2006) (examining the impact of "critical race feminists" on understanding and challenging subordination and oppression, and the related catalytic role in effecting societal change).

¹⁶⁴ Adrien K. Wing & Christine A. Willis, *From Theory to Praxis: Black Women, Gangs, and Critical Race Feminism*, 11 LA RAZA L.J. 1, 3 (1999) (identifying two sources of influence on CRF from legal studies: deconstruction and legal canon analysis).

¹⁶⁵ J. M. Balkin, *Deconstructive Practice and Legal Theory*, 96 YALE L.J. 743, 744 (1987) (describing three reasons that deconstruction would be of interest to attorneys as a method of legal analysis).

¹⁶⁶ Wing & Willis, *supra* note 164, at 2-3 (illustrating the role that deconstruction and, more generally, critical legal studies play in exposing the relationship between law and other societal concepts, and noting their impact on critical race feminism).

- c. How law creates and maintains race-based power imbalances.
- d. How law intersects with the collective racial histories of the respective racialized groups in the U.S.
- e. Why social burdens or benefits accrue because of race.
- f. Why narratives are used to express and examine racial identities.
- g. Why legal discrimination needs the concept of intersectionality, (i.e., the interlocking oppressions affecting women, such as racism, sexism, heteropatriarchy, classism, agism, etc.).¹⁶⁷

The fusion of the delineated inquiries into medical education would prove beneficial for addressing the need for culturally competent curricula. Montoya correctly points to the propensity of medical schools to “rarely name or analyze” race in terms of its socially constructed nature and resulting social inequalities.¹⁶⁸

Montoya notes innovative efforts by medical schools to address cultural competence and its shortcomings:

[I]n the Videotape: Worlds Apart: A Four-Part Series on Cross-Cultural Healthcare produced by Stanford University Center for Biomedical Ethics (2003) wherein the narrator, Robert Phillips ‘makes a passing reference to the Tuskegee experiments’ to explain the distrust that many African Americans have of doctors and the health profession. . . [accompanied by] a one sentence slide that purports to explain to the Stanford medical students what the Tuskegee experiments were.

A critical examination of the Tuskegee Syphilis Study is necessary in order to adequately make a deconstructive inquiry into its biomedical significance to women and research. Champion notes an example of using the Tuskegee Syphilis Study as a means to illicit discussion on professional responsibility in informed consent and scientific experimentation issues amongst college students enrolled in a physical therapy education course:

The Syphilis study was used as a teaching example – it should

¹⁶⁷ Montoya, *supra* note 74, at 1317-18 (listing examples of issues dealing with social identity and inequality that are almost never addressed in medical school teaching materials).

¹⁶⁸ *Id.* at 1317.

be noted that none of the students were familiar with the study. The six-hour instructional unit included 1) in class viewing of the video, *Miss Evers Boys*, 2) individual student completion of a “Probing Question Guide” to define ethical dilemmas and consider value conflicts, and 3) focused discussion about issues such as medical paternalism, autonomy, informed consent, honesty, “whistle-blowing”, and the conflict between scientific inquiry and patient rights; as complicated by role definition and responsibility within the health care system. . . . 64 of the 68 students (95%) reported that this instructional approach was more satisfying than traditional formats used in applied ethics. Specific outcomes of this experience were described in terms such as “. . .brought theory to life in the classroom”, “now understanding the underlying value of valid informed consent”, “will not soon forget this violation of human dignity and its impact”, and “. . . learning from the experience of others helps me to clarify the issues.” At the conclusion of the unit, 100% of the students requested additional time for further discussion.¹⁶⁹

The reality that none of the students were familiar with the Tuskegee Syphilis Study prior to the viewing of the 1997 HBO movie, *Miss Evers Boys*,¹⁷⁰ is especially disturbing because the “facts” of the study are now skewed by a fictional account of a significant human atrocity in U.S. medical history that marginalizes the women of the Tuskegee Study directly impacted by the effects of untreated syphilis. It is the “rarely named or analyzed” prevailing issues that CRF cast light upon in order to promote a curricular delivery that meets the current medical accreditation cultural competency standards.

B. Miss Evers Boys and the Tuskegee Syphilis Study

The 2003 Institute of Medicine (IOM) Report, *Unequal Treatment*, documented the depth of racial and ethnic disparities in U.S. healthcare, using a variety of outcome and process measures.¹⁷¹ Medical education through the advancement of culturally competent curriculum has the opportunity to address the existing gap in U.S. healthcare among racial and

¹⁶⁹ Walter T. Champion, *The Tuskegee Syphilis Study as a Paradigm for Illegal, Racist, and Unethical Human Experimentation*, 37 S.U. L. REV. 231, 243 (2010).

¹⁷⁰ See Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 990-91; see also GRAY, *supra* note 4, at 109 (noting that “[m]any of the men involved in the study were deeply offended by [the movie version]. which they felt misrepresented them and the facts of the studv”).

¹⁷¹ BRIAN D. SMEDLEY ET. AL., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* 420 (National Academies Press 2003).

ethnic populations. This can be accomplished by shaping an “ethical conscience”¹⁷² infused with CRF theory. Professor Patricia A. King notes that the “social and ethical issues that the [Tuskegee] experiment poses for medicine, particularly for medicine’s relationship with African Americans, are still not broadly understood, appreciated, or even remembered.”¹⁷³ CRF has the potential to close the gap of racial and ethnic disparities through the application of a transformative remedy that utilizes a reproductive justice framework under the auspice of medical education. Cinemeducation¹⁷⁴ provides a venue to use film as part of the classroom curriculum to “promote enthusiasm for learning, highlight themes, enhance discussion and reflection, and sometimes, help illustrate specific teaching points on clinical topics, social and health care policy issues, cultural differences, and science.”¹⁷⁵ However, the showing of a film to teach or integrate medical ethics does not replace “thoughtful reading and analysis of essential texts.”¹⁷⁶

A CRF lens would allow one to see the HBO movie, *Miss Evers Boys*, erroneous act of imputing power and privilege to Eunice Rivers, the sole Black nurse involved against the U.S government sponsored PHS study of untreated syphilis on unsuspecting Black males. Public misconceptions about the Tuskegee Syphilis Study are not only prominent in the media, [but can] “carry serious implications for attitudinal and behavioural outcomes related to the healthcare of African Americans.”¹⁷⁷ *Miss Evers Boys* is a “widely popular interpretation of the events of the study.”¹⁷⁸ Dula

¹⁷² Jay Katz, *Human Experimentation and Human Rights*, 38 ST. LOUIS U. L.J. 7, 9 (1993) Katz notes that the regulations of the human experimentation process after Auschwitz and Tuskegee “questioned by some, that reliance on the ethical conscience, inculcated in physician-investigators during their medical education, provided insufficient protection to the human rights of subjects of medical research.” See also, HOLLOWAY, *supra* note 7, at 23 (noting how the Tuskegee Study is used in Bioethics to teach about ethical oversight); See JAY KATZ, ET AL., EXPERIMENTATION WITH HUMAN BEINGS THE AUTHORITY OF THE INVESTIGATOR, SUBJECT PROFESSIONS AND THE STATE IN THE HUMAN EXPERIMENTATION PROCESS (1972); For a commentary on Katz’s seminal work on Human Experimentation, Larry I. Palmer, *The High Priests Questioned or at Least Cross-Examined*, 5 RUTGERS-CAM. L. J. 237 (1973-74).

¹⁷³ Patricia A. King, *The Dangers of Difference*, 22 HASTINGS CENTER REP. 35, 35 (1992).

¹⁷⁴ See generally, MATTHEW ALEXANDER, PATRICIA LENAHAN & ANNA PAVLOV, CINEMEDUCATION: A COMPREHENSIVE GUIDE TO USING FILM IN MEDICAL EDUCATION (2005) (“Cinemeducation,” a word and method coined by editor Matthew Alexander. The guide includes short clips to assist medical educators and beyond).

¹⁷⁵ Henri Colt, Silvia Qadrelli and Lester Friedman, *The Picture of Health: Medical Ethics and the Movies*, preface v (2011).

¹⁷⁶ *Id.* at preface vi.

¹⁷⁷ J. Wasserman, M.A. Flannery & J.M. Clair, *Raising the Ivory Tower: The Production of Knowledge and Distrust of Medicine Among African Americans*, 33 J. MED. ETHICS 177, 179 (2007).

¹⁷⁸ *Id.* The play was written by David Feldshuh (1995) and shown as a HBO television film in 1997.

correctly points out that “the film actually opens a broader discussion regarding many ethical concerns.”¹⁷⁹ The fictional account of *Miss Evers Boys* will become “fact” unbeknownst to the viewer/student if not explored critically in curricular delivery to teach about the Tuskegee Syphilis Study. There is a deconstructive approach to critically examine some aspects of the movie, in both historical and fictional contexts. Ironically, the “dramatizations of the Study. . . focused in large measure on the role of the woman who worked with the participants for practically its entire duration.”¹⁸⁰ However, in fact, the 1973 lawsuit (amended on August 1, 1974)¹⁸¹ filed by Attorney Fred Gray on behalf of four categories of plaintiffs (living syphilitics, living controls, personal representatives of the estates of deceased syphilitics, and personal representatives of the estates of deceased controls) did not include Nurse Rivers or the Tuskegee Institute as defendants in the case.¹⁸² Gray reasoned that:

Miss Rivers was powerless to have either begun, continued, or stopped the program. She worked in an environment where all of her superiors were white, while she worked directly with African American men. Even after penicillin became available, Nurse Rivers had no voice as to whether or not [the] men would be given penicillin.¹⁸³

¹⁷⁹ Annette Dula, *Research and Racism: Miss Evers' Boys in Cinemeducation: A Comprehensive Guide to Using Film in Medical Education* 80-83, (Matthew Alexander, Patricia Lenahan & Anna Pavlov eds. Oxford University Press 2011). She suggests several questions for consideration:

1. Maintaining the line between care and research.
2. Unequal power relations.
3. Conflicts of interest.
4. Communication between black patients and white doctors.
5. Health disparities.

¹⁸⁰ GRAY, *supra* note 4, at 109; See also Larry I. Palmer, *Jay Katz: From Harms to Risks*, 6 YALE J. HEALTH POL'Y, L. & ETHICS 455,458. Author relays a conversation with playwright David Feldshuh prior to showing it a Sundance Festival:

David was not concerned, as some critics were, with the politics of race and gender that might overshadow his attempts, as a white, male, Jewish physician-playwright, to portray the fictitious heroine of his play—an African-American public health nurse. Rather, he was concerned with his portrayal of the African-American physician. The implication—albeit a fictitious one—that Dr. Brodus, a black physician, was somehow involved in a study condemned as unethical and racist would raise some special issues.

¹⁸¹ *Id.* at 84. (The initial lawsuit was filed on July 24, 1973. Jurisdiction invoked under (1) U.S. CONST. amend. IV, V, VIII, IX, XIII, XIV; (2) 42 U.S.C. §1981, 42 U.S.C. §1985(3), and 42 U.S.C. § 2000(D); (3) the Federal Torts Claims Act, 28 U.S.C. §267; (4) the federal common law, and (5) the Constitution, statutes, and common law of Alabama).

¹⁸² *Id.* at 84-86 (noting that “[t]he defendants were the United States of America, Casper Weinberger as Secretary of the Department of Health, Education, and Welfare, Dr. Ira. I. Myers, State Health Officer; Dr. John R. Heller, individually, Dr. Sidney Olansky, individually, and others”).

¹⁸³ *Id.* at 85, In contradiction to the movie *Miss Evers Boys*, “Nurse Rivers did not give penicillin to one participant and withhold it from all the others.” In fact, “[t]he film conspicuously omits the role that the State of Alabama, through its health agencies, played in the Study. The Alabama Health

Gray noted that during the beginning era of the experiment in the 1930s, the Tuskegee Institute was an African American educational institution struggling to survive, and its cooperation was being sought by the federal government; It began as an outgrowth of the Rosenwald Fund survey, and was financially backed by Tuskegee Institutes' significant benefactor.¹⁸⁴ "[Gray] felt the same about the Tuskegee Institute as [he] did about Nurse Rivers – that the Institute and its officials were misled, betrayed, and taken advantage of [by the federal government]."¹⁸⁵ The surviving Tuskegee Study participants' objections to *Miss Evers Boys* lay the foundation for a deconstructive inquiry setting forth "CRF Critical Teaching Points," which ultimately address how law intersects with the collective racial histories of the racialized groups in the U.S.¹⁸⁶ "The entire film shifts the responsibility for the Study from the federal government to an African American doctor and an African American nurse. [The] Study was conceived, financed, executed, and administered by the federal government. The African American medical professionals who participated in it were victims as were the 623 African American participants."¹⁸⁷ As to the role of Nurse Rivers in the Tuskegee Syphilis study, inasmuch that it is erroneously depicted in *Miss Evers Boys*¹⁸⁸ or a fictionalized account, it should be noted that the oft-cited historical account of the study, *Bad Blood*, by James H. Jones, "devotes a major portion of [the book] to describing Nurse Rivers' work and the trusting relationships she established with the men in the study."¹⁸⁹ Hammonds argues that:

[Jones] spends far too little time documenting [Nurse Rivers] relationship with the black and white male physicians who supervised her. Castigating [Nurse Rivers] for "ethical

Department cooperated with the federal government in continuing not to treat the participants after penicillin became available, notwithstanding that Alabama laws required such treatment." *Id.* at 110-11.

¹⁸⁴ *Id.* at 86 (explaining the origins of the Tuskegee Institute).

¹⁸⁵ *Id.*; *Contra* Larry I. Palmer, *Paying For Suffering: The Problem of Human Experimentation*, 56 MD. L. REV. 604, 610(1997) Palmer argues:

[Gray's] theory [of racial selection] fails to account for the importance of institutional arrangements as an explanation of what happened to his clients – the Caucasian public health physicians named as defendants in the lawsuit relied upon African-American physicians to refer syphilitic patients to the Public Health Service for over forty years . These African-American physicians should at least be viewed as co-investigators, rather than as anonymous African-American professionals victimized by "the system."

¹⁸⁶ *See* Montoya, *supra* note 74, at 1319 (identifying the author's objective to inject the core ideas and values of CRF into various aspects of educational reform).

¹⁸⁷ GRAY, *supra* note 4, at 110 .

¹⁸⁸ *Id.* (highlighting significant misrepresentations in the HBO film regarding the care provided by nurses in Tuskegee).

¹⁸⁹ Hammonds, *supra* note 8 at 345 (examining the Tuskegee Study and the official role of Nurse Rivers).

passivity," Jones seems almost personally aggrieved that Nurse Rivers was unable to stop the experiment. [Jones] does not call to account the male physicians who had much more power and authority than she. Thus, in [Jones'] rendering of ["a historical account"- added by author] the story, the black woman nurse becomes the center of the ethical dilemmas raised by the Tuskegee Study. The person who in fact had the least amount of power to resist or question the study is blamed.¹⁹⁰

As Susan M. Reverby puts it, "Tuskegee's symbolic importance makes it culturally difficult, however, to consider the seeming 'facts' of the study alone. Especially after the 1997 presidential apology, media and cultural attention have refocused on Tuskegee and its racial assumptions and made the facts still more elusive."¹⁹¹ It is an inherent goal of CRF Teaching Points to allow students to critically analyze the elusive and obvious facts, in order to derive a conclusion that ultimately seeks to right historical and present day wrongs by providing culturally competent curricula. ¹⁹² As to the Tuskegee Syphilis Study and its biomedical significance in U.S. medical history, Herman Shaw, the 95-year-old survivor who attended the White House Presidential apology sums it up best: "We were treated unfairly. To some extent like guinea pigs. We were not pigs. We were hard working men, not boys and citizens of the United States."¹⁹³ CRF has the potential to enhance medical educations' goal of satisfying cultural competence accreditation standards by applying a reproductive justice

¹⁹⁰ *Id.*

¹⁹¹ Susan M. Reverby, *More Than Fact and Fiction: Cultural Memory and the Tuskegee Syphilis Study*, 31 HASTINGS CENTER REP. 23, 25 (2001) (discussing how the "illuminating misconceptions" surrounding Tuskegee Syphilis Study actually provide insight into the significance of the study).

¹⁹² For other resources see the video, *The Deadly Deception*, a well-produced documentary (produced by Nova, WGBH Educational Foundation, available from Films for the Humanities and Sciences) on the Tuskegee Syphilis Study. See also, Bryan & Peggy Y. Byers, *The Deadly Deception*, 2(4) J. OF CRIM. JUST & POP. CULTURE 93-95 (1994). A review of the documentary notes:

The utilization of interviews with two survivors of the experiment, Herman Shaw and Charles Pollard, and experts in the fields of research, medicine, and civil rights, along with original film taken during the experiment, results in a believable and startling portrayal of the misuse of human subjects in scientific research.

See also, CORNELL UNIVERSITY, SUSCEPTIBLE TO KINDNESS: MISS EVER'S BOYS AND THE TUSKEGEE SYPHILIS STUDY, (1994) a prize winning educational video that examines the ethical issues raised by the Tuskegee Study of Untreated Syphilis in the Negro Male (1932-1972). A study guide (Professor Larry I. Palmer, executive producer and author)for Discussion Leaders on the video is available. Professor Larry I. Palmer.

¹⁹² Champion *supra* note 198, at 242; See also GRAY, *supra* note

¹⁹³ See Champion, *supra* note 175, at 242 (describing the Tuskegee Syphilis Study as "Nazi-like" experimentation); see also GRAY, *supra* note 4, at 111 (noting that the surviving participants of the study viewed *Miss Evers' Boys* as "a tremendous insult and a gross misrepresentation" for its depiction of the four participants as "dancers and "shuffling sams" who lived a carefree existence of drinking, dancing, singing, and cutting up" even though "[t]he men who participated in the Study, for the most part, were hard-working reputable persons in their communities").

framework.

C. The Her-Story¹⁹⁴ of the Women of the Tuskegee Syphilis Study

CRF theory embodies “[t]he use of narrative, chronicles, and storytelling. . . among the tools often used by CRF theorists.”¹⁹⁵ Professor Montoya asserts that “[d]efining the voices of CRF means forming allies in the task of dismantling the barriers of race and gender and having those allies take CRF concepts and use them so that they mean something real for women of color themselves, our local communities, and future generations.”¹⁹⁶ One must explore the CRF Critical Teaching Point of the use of narrative to acknowledge the existence of the women who were directly impacted by the Tuskegee Syphilis Study, but who were marginalized during the study in 1932 and in its present day recounting. According to Critical Race Feminist Scholar, Adrien K. Wing, “narratives aid in exposing the reality of racism and validate the experiences of people of color.”¹⁹⁷ As a critical teaching tool, “[t]he lens of CRF compels the storyteller [“teacher”] to not only speak about “unspeakable” things, such as notions of race and racial construction, gender, and locations of power in the health care system – it also encourages the story listener [“student”] to hear the silence of issues raised but not adequately addressed.”¹⁹⁸ The fact

¹⁹⁴ I have defined “Her-story,” in an earlier writing as: the Black woman’s story, [which] cannot be maintained in the background of history. The Black woman’s body has known reproductive regulations and reproductive restraints. Her womb has been used as a reproductive resource center and as a receptacle dumping ground for the sexual pleasure of those in power. The Black woman’s womb has been viewed as a contagion subjected to sterilization laws and abuses. Her womb has served and continues to serve as a discovery zone for the experimentation of contraceptives under the auspice of welfare reform or for the sake of advancing scientific knowledge.” Washington, *Every Shut Eye*, *supra* note 67, at 128-29. In this paper, the her-story of the women of the Tuskegee Syphilis Study lies in the fact that that same body is not deemed worthy to research “her” specific injuries due to the exposure of untreated syphilis – which merits biomedical significance to women and research in U.S. medical history.

¹⁹⁵ Deleso Alford Washington, *The Anatomy of a “Pantsuit”: Performance, Proxy and Presence for Women of Color in Legal Education*, 30 HAMLINE J. PUB. L. & POL’Y 605, 613 (2009) (citing Derrick A. Bell, *Who’s Afraid of Critical Race Theory*, 1995 U. ILL. L. REV. 893, 899 (1995)); see generally CRITICAL RACE THEORY: THE KEY WRITINGS THAT FORMED THE MOVEMENT (Kimberle Crenshaw, Neil Gotanda, Gary Peller & Kendall Thomas eds., The New Press 1995) (exploring the role of law in creating American racial hierarchy using components of Critical Race Theory); CRITICAL RACE THEORY: THE CUTTING EDGE (Richard Delgado & Jean Stefancic eds., Temple University Press 2000) (challenging the way Americans look at race, liberalism and sexuality using Critical Race Theory).

¹⁹⁶ Montoya, *supra* note 74, at 1310-1311.

¹⁹⁷ Deleso Alford Washington, *Hurricane Katrina and Collective Identity: Seeing Through A “Her-historical Lens”*, 31 NOVA L. REV. 325, 329 (2007) (citing Adrien K. Wing & Christine A. Willis, *From Theory to Praxis: Black Women Gangs and Critical Race Feminism*, 11 LA RAZA L.J. 1, 3 (1999)) (addressing Hurricane Katrina from the perspective of Critical Race Theory).

¹⁹⁸ Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 982-83.

that history marginalizes or silences the particular experience of the women directly impacted in the Tuskegee Syphilis Study can be explored by extracting the "*narrative behind the narrative*," a concept which challenges the world view of the historically accepted narrative by offering exposure to alternate social realities.¹⁹⁹ The historically accepted narrative of the Tuskegee Syphilis Study generally focuses upon the government initiated untreated syphilis study on Black males from 1932-1972. An alternate social reality centers on the fact that syphilis is a sexually transmitted disease that was unwittingly passed on to the wives and partners of the men in the study who were not selected as research subjects based upon their gender.²⁰⁰ This *narrative behind the narrative* sheds light on the autonomy (or lack thereof) of the women directly impacted as wives,²⁰¹ as well as the presumed illegitimacy of relationships outside of the legal category of marriage.

It was not until 1975 that the wives, widows, and offspring were added to the Tuskegee Health Benefit Program, which granted lifetime medical benefits and burial services to all living participants pursuant to the out-of-court settlement filed on behalf of the study participants and their families in 1973.²⁰² Therefore, Black women who were married to the male participants were not deemed worthy of treatment nor did they fit the all black male research protocol during the study's 40-year span. Likewise, the women directly impacted but not married to the male participants of the Study, and the children manifesting congenital syphilis but borne out of wedlock, were not recognized and thus did not receive a remedy for the harm resulting from the governmental experiment. Professor Martha Fineman states that "[i]n a diverse and secular society, it is impermissible for the state to privilege one form of sexual affiliation over others, and thus to make marriage the core connection in the institution of the family."²⁰³ By exploring the *narrative behind the narrative* of the women directly impacted by the Tuskegee Syphilis Study and deconstructing the notion of

¹⁹⁹ *Id.* at 984.

²⁰⁰ Bridgewater, *supra* note 65, at 411 (agreeing that "[t]he story creates a disturbance in the accepted discourse and such disturbances (indeed all disturbances) are inherently valuable").

²⁰¹ See MARTHA ALBERTSON FINEMAN, *THE AUTONOMY MYTH: A THEORY OF DEPENDENCY* 74 (2004) (asserting that "[m]arriage in the civil societarian's hands become much more than a legal category. It is reconfigured into the mantle of morality, from both a societal and an individual standpoint. Marriage is presented as the path to personal and familial (and therefore societal) salvation.").

²⁰² JONES, *supra* note 3, at 215 (noting that "[n]ot until two years after medical services were supplied for the men were provisions made for their families. In 1975 the government extended treatment to the subjects' wives who had contracted syphilis and their children with congenital syphilis.").

²⁰³ See FINEMAN, *supra* note 199, at xxx.

marriage and its presumed benefits, one can ultimately address why legal discrimination needs the concept of intersectionality (i.e. the interlocking oppressions affecting women, such as racism, sexism, heteropatriarchy, classism, agism, etc.)²⁰⁴ in order to serve as a CRF Critical Teaching Point.

Law and society have created and maintained a lack of space with regard to the Black women directly affected by the Tuskegee Syphilis Study. Law and society created constructs of “legitimate and illegitimate sexualities” expressed by Black women, as well as a normative standard concerning sexuality and marriage.²⁰⁵ There exists a narrative worth critically examining as to the different tropes of Black women that were affected by the Study, who have been similarly and dissimilarly marginalized in historical and contemporary discussion due to socio-legal constructs of “legitimate and illegitimate sexualities.” Holloway posits that “[i]t is certainly true that the field of bioethics might benefit from increased exposure to the categories of stories, theories of analysis, and the study of genre.”²⁰⁶ Specifically, there is a notion of married Black women embodying a “constructive presence” within law and society via their husbands, and single Black women embodying an “invisible presence” because of their lack of a husband. The interaction of law and society has made single, Black women essentially invisible to the point that the framing of their rights has either been severely limited, completely denied, or simply unacknowledged. Conversely, the interaction of law and society has made Black married women constructively present via their husbands. The Tuskegee Syphilis Study warrants a critical examination of the different life experiences of marginalization, even amongst Black women, based on marital status and presumptions of legitimacy (or the lack thereof). Thus, there exists a real need to critique the rights and remedies accrued or denied to Black women because of intersecting or multiple identities stemming from their race, gender, and marital status, both historically and presently.

Medical schools benefit from the integration of CRF theory into their curricula.²⁰⁷ The utilization of a transformative remedy that focuses on the

²⁰⁴ Montoya, *supra* note 74, at 1317-1318.

²⁰⁵ See generally AFRICAN AMERICAN POLICY FORUM, A PRIMER ON INTERSECTIONALITY 2, available at http://aapf.org/wp-content/uploads/2009/03/aapf_intersectionality_primer.pdf (explaining that “[o]ne of the most significant aspects of current social justice practice that warrants rethinking, is the dominance of a particular orientation that disaggregates social problems into discrete challenges facing specific groups. These groups are often defined in mutually exclusive ways, generating artificial distinctions and sometimes conflicting agendas.”).

²⁰⁶ HOLLOWAY, *supra* note 7, at 149.

²⁰⁷ See generally Montoya, *supra* note 74, at 1314 (noting that “[h]ealthcare institutions are making a coordinated and comprehensive effort to educate healthcare providers about linguistic and

root causes for the historical and current omission of the women directly impacted by the Tuskegee Syphilis Study is enhanced through CRF Critical Teaching Points which advocate the use of deconstructive techniques and narrative.

CONCLUSION

Current discourse will at times admit that the Tuskegee Syphilis Study exploited Blacks as living subjects for purposes of "scientific advancement" to ultimately prove race based differences. This was a historical tragedy that laid the foundation for mandates on conducting research on human subjects. However, an overlooked extension of the aforementioned historical tragedy is the 'her-story' of the Black women of Tuskegee who were directly impacted by the study. Medical education currently recounts the most noted biomedical research study on human subjects, but without critically examining the marginalization of the Black women directly impacted. These women were not only worthy of being acknowledged then, but are worthy today of acknowledgement during recounts of the Tuskegee Syphilis Study. A transformative remedy that utilizes a reproductive justice framework would address the biomedical significance of women and research in the Tuskegee Syphilis Study. The implementation of culturally competent curricular content delivery that satisfies medical education accreditation standards as to the teaching of the Tuskegee Syphilis study would serve as a necessary step toward addressing race, gender, and research disparities in the healthcare field. Thus, a culturally competent curriculum could assist in the attainment of reproductive justice and lead to an increased trust of public health initiatives within the African American community.

cultural competence, which emphasizes the importance of understanding culture and language in providing quality care to minorities. Medical schools are busy developing courses and materials that address this competence requirement."); Washington, *Critical Race Feminist Bioethics*, *supra* note 61, at 996 (explaining "that CRF Bioethics enhances the ability of medical practitioners to humanize present interactions with diverse populations based on knowledge of a historically marginalized past narrative involving medical technology, specifically the specialty of gynecology and the advancement of this specialty through the laws of enslavement"); For greater discussion on critical race theory, see Kimberle Williams Crenshaw, *The First Decade: Critical Reflections, or "A Foot in the Closing Door,"* 49 *UCLA L. REV.* 1343 (2002); Athena D. Mutua, *The Rise, Development and Future Directions of Critical Race Theory and Related Scholarship*, 84 *DENVER. U.L. REV.* 329 (2006); Angela P. Harris, *Theorizing Class, Gender, and the Law: Three Approaches*, 72 *LAW & CONTEMP. PROBS.* 37 (2009).

