

# Journal of the Black Catholic Theological Symposium

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Volume 3

Article 5

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12-1-2009

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### Recommended Citation

Daniels-Sykes, Shawnee M. S.S.N.D. (2009) "Code Black: A Black Catholic Liberation Bioethics," *Journal of the Black Catholic Theological Symposium*: Vol. 3, Article 5.  
Available at: <https://ecommons.udayton.edu/jbcts/vol3/iss1/5>

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# Code Black: A Black Catholic Liberation Bioethics

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*Based on a paper delivered during the 2008 Annual Meeting in Chicago, Daniels-Sykes, SSND proposes that the long history of neglect and abuse suffered by blacks at the hands of the health care industry results from entrenched assumptions fostered by Western philosophies and principles that guide mainstream medical ethics, particularly in light of the 1979 Belmont Report, produced in response to the infamous Tuskegee Syphilis Study. That the report failed to take into consideration the circumstances of poverty and race, factors key to our understanding those victimized by the Study, underscores the prevailing implicit assumptions of black inferiority. Daniels-Sykes, SSND advises that a black Catholic liberation bioethics must be developed, one that promotes a culture of life.*

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Worldwide hospital emergency codes are frequently denoted by a color: code red, code blue, code yellow, or code black. For each hospital the code color has a special denotation. A code red could mean a patient is having a heart attack and needs emergency attention; a code blue could refer to an emergency in the neonatal intensive care unit that needs

a response; a code black could indicate massive casualty or other health threats experienced by black people that need to be addressed. No matter the code color when an emergency is announced a particular code team is summoned to come immediately to the rescue, to save a human life(s). This paper proposes that the history of racist medicine, the use of Western philosophic theories and principles that undergird mainstream bioethics, and black mistrust of the health care system and health care providers are primary reasons for the black health crisis in the USA that has an extensive history. In an August 2008 article, researchers from the Department of Medicine at the University of Minnesota acknowledge that:

[o]ver the past two decades, a burgeoning literature has emerged that documents the deleterious effects of perceived discrimination on the health of racial and ethnic minorities, including poor mental health (e.g., depression, anxiety, psychological distress), poor physical health (e.g., cardiovascular disease, breast and prostate cancers), giving birth to preterm or low birth weight babies, and deleterious health behaviors such as smoking and alcohol use.<sup>1</sup>

As a result of this crisis, I believe that a ‘code black’ alarm needs to ring loudly, signifying the need to address and resolve the massive crisis in black health. The code calls forth lay health advocates to offer assistance to patients and clients

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<sup>1</sup> Diana J. Burgess, Yingmei Ding, Margaret Hargroves, Michele van Ryan, Sean Phelan, “The Association between Perceived Discrimination and Underutilization of Needed Medical and Mental Health Care in a Multi-Ethnic Community Sample.” *Journal of Health Care for the Poor and Underserved* 19 (August 2008): 895.

in order to relieve this crisis in black health. Creative and concrete ways are needed to liberate these ailing captives from: acute and chronic illnesses that might have been prevented, physical, social, and psychological disabilities that might have been prevented, and/or premature deaths that might also have been prevented, among others. The highly disproportionate rate of morbidity and mortality in the black community as compared to whites is the impetus for my idea of a Black Catholic liberation bioethics.

Black people hail from a culture of deep religious roots; they have found meaning in pain and suffering through the black spirituals and reflection of the paschal mystery of the Black Jesus. While acknowledging a mainstream secular approach to bioethics and highlighting a Black Catholic liberation bioethics, I discuss the black health crisis that persists, especially because a purely modern secular bioethical lens has been used to evaluate all ethical concerns in health care via the renowned *1979 Belmont Report*.<sup>2</sup> I maintain that in order for a black Catholic liberation bioethics to emerge that promotes a culture of life instead of a culture of death, the emphasis must be on black self-love, black self-esteem, black self-care, and black self-empowerment. A black Catholic liberation bioethics implies: a love for justice, active instead of passive-aggression, liberation, reconciliation, peacefulness, community, trust, honesty, authenticity, a listening heart, great communication skills, a tireless ability to negotiate the health

<sup>2</sup>The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1979). See the National Institutes of Health website: <http://ohsr.od.nih.gov/guidelines/belmont.html>.

care system, as lay health advocates assist patients in responding proactively to significant health issues that stifle Black human flourishing. Constant are prayers and actions toward freedom from oppression, depression, anger, and anxiety. Of crucial importance is stopping the dysfunctional dance between white racism and black internalized oppression. Acknowledging that overt and covert racism persist are of great importance in addressing the black health crisis. Essential also is the vow not to be succumbed by this social evil. The onus is on members of the black community who must first move out of a victim stance or a finger pointing stance, to one that embraces black self-empowerment, black self-esteem, black self-care, and black self-love in order to cope directly with this enduring crisis in black health that is driven by our dance of racial oppression, fear, mistrust, and suspicion of the health care system and health care providers.

In this paper, I argue that the U.S. Government's promulgation of the July 1979 *Belmont Report*,<sup>3</sup> which includes ethical principles and guidelines for the protection of human subjects of research, ignores the long history of unethical medical treatment of black people in the American health care system and medical research institutions. The report, instead, contains four mid-level principles (i.e., respect for persons, beneficence, non-maleficence, and justice) which are derived from Western European philosophical

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<sup>3</sup> Albert Jonsen, "On the Origins and Future of the Belmont Report," in *Belmont Revisited: Ethical Principles for Research with Human Subjects*, eds. James Childress, Eric M. Meslin, and Harold T. Shapiro (Washington, D.C.: Georgetown University Press, 2005), 3-12.

theories such as Immanuel Kant's deontology and categorical imperative, John Stuart Mill's utilitarianism, John Rawls' egalitarianism and social contractarianism, and Robert Nozick's libertarianism. Although no one single universal philosophical ethical theory could be deduced to create the four principles of bioethics, both the theories and principles play a huge role in the promotion of normative bioethics, or modern secular bioethics. These theories and principles are considered to be unbiased, impartial, universal, coherent and all-encompassing rather than focus on one's particular experience or social location. Essentially, they are considered good ethical theory and principles in the ethical decision-making process and are to be judiciously employed to safeguard human beings from physical and psychological harm in the research and/or clinical setting. I push for a black Catholic liberation bioethics as another approach to addressing the black health crisis and other bioethical concerns that continue to adversely affect black people.

To develop my argument, I propose: 1) to present an overview of the history of medical abuse of black people by members of US medical and research establishments; 2) to discuss the influence of the July 1979 *Belmont Report*, which is a direct response to the forty-year Tuskegee Syphilis Study on poor uneducated black men in Macon County Alabama, and finally; 3) to begin a discussion on what I am calling a black Catholic liberation bioethics as exemplified in a ministry of accompaniment that involves lay health advocates in relationship with patients/clients.

## Overview of Blacks' Experiences in Health Care

Since the time of African chattel slavery, blacks have been the subject of research and medical abuse. According to bioethicist and journalist Harriet A. Washington, “[e]nslavement could not have existed and certainly could not have persisted without medical science. Physicians were very much dependent upon slaves, both for economic security and for the enslaved ‘clinical material’ that fed the American medical research and medical training that bolstered physicians’ professional advancement.”<sup>4</sup> The dialog *Dissecting Hall*, e.g., describes the way blacks were unwillingly and unwittingly dragged off for medical experimentation. Composed in the Antebellum Period, *Dissecting Hall* illustrates this notion about “clinical material,” and refers very graphically to the blacks being kidnapped and cruelly used, through the removal of their organs and limbs, to satisfy scientific curiosity.<sup>5</sup> Blacks during the Antebellum Period had little control over medical decisions made to use their bodies or even to use their corpses

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<sup>4</sup> Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans From Colonial Times to the Present* (New York, New York: Doubleday Broadway Publishing Group, 2006), 26.

<sup>5</sup> This dialog was found in an article by Todd L. Savitt and is called “The Use of Blacks for Medical Experimentation and Demonstration in the Old South.” *Journal of Southern History* 48 (August 1982): 341-2. In a footnote he gives credit to Anne Donato for the reference, which is preceded by this citation *Scribe* I (December 1951), 17. Unfortunately, I was not able to find the source to verify the conversation.

for medical research.<sup>6</sup> Medical personnel believed that blacks were different from whites and thus, inferior. From research on human bodies, for example, scientists documented that whites had the largest skulls, the largest brains, and were thus, the most intelligent with the best character of all the human beings.<sup>7</sup> To the contrary, Blacks had the smallest skulls, the smallest brains, and were thus, considered unintelligent with no character.<sup>8</sup>

During the eighteenth and nineteenth centuries, medical researchers continued to practice on blacks to develop their trade or clinical techniques. The Father of Surgical Gynecology, Dr. Marion Sims, for example, used African female slaves to perfect his vaginal-vesicular surgical procedure.<sup>9</sup> Sims repeatedly performed painful surgeries on twenty-six of these women who suffered from vaginal fistulas. His experimentation led to the development of a forerunner of the modern speculum. Moreover, experimentation with new treatment and drugs on slaves allowed Dr. Robert Jennings to be credited with the development of successful vaccination

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<sup>6</sup> *Ibid.*, 331-48.

<sup>7</sup> Harriet A. Washington, *Medical Apartheid*, 35

<sup>8</sup> *Ibid.*, 35.

<sup>9</sup> LL Walls, "The Medical Ethics of Dr. J. Marion Sims: A Fresh Look at the Historical Record." *Journal of Medical Ethics* 32 (2006): 346-50; Leon R. Kapsalis, "Mastering the Female Pelvis: Race and the Tools of Reproduction," in *Skin Deep: Spirit Strong: The Black Female Body in American Culture*, ed. Kimberly Gisele Wallace-Sanders (Ann Arbor, Michigan: University of Michigan Press, 2002), 263-300.



against typhoid infection that resulted from his successful experimentation on thirty slaves and free blacks.<sup>10</sup>

Three twentieth century examples of medical experimental abuse and neglect toward blacks are as follows: The first concerns a 31-year-old black woman named Henrietta Lacks. In February 1951, when she walked through the doors of Johns Hopkins Hospital in Baltimore, Maryland bleeding profusely, she did not live to see that she would make Dr. George Gey famous only ten months after she died. Gey used Lacks' peculiar and highly potent cells to develop a medical specialty called a continuous cell-line, or HeLa cells.<sup>11</sup>

A second medical experimentation pertains to the United States Public Health Services Study, more popularly known as the Tuskegee Syphilis Study which lasted from 1932 to 1972. It involved 399 poor uneducated black men from Macon County Alabama. This government-sponsored experiment's main goal was to watch the progression of untreated syphilis in these men. It is important to note that another two hundred and one men comprised the control group. Whether in the experimental or control group, the human rights and dignity of

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<sup>10</sup> Barbara L. Bernier, "Class, Race, and Poverty: Medical Technologies and Socio-Political Choices." *Harvard Blackletter Law Journal* 115 (1994): 119.

<sup>11</sup> W. Michael Byrd and Linda A. Clayton, *An American Health Dilemma: Race, Medicine, and Health Care in the United States: 1900-2000* (New York, New York: Routledge, 2002), 285-6.

these men were not only suppressed, but egregiously violated for forty years.

A third example refers to the 1960s and 1970s where illegal sterilizations were performed on black women without their informed consent and for no apparent medical reasons. “The violence was committed by doctors paid by the government to provide health care for these women. Teaching hospitals performed unnecessary hysterectomies on poor black women as practice for their medical residents.”<sup>12</sup>

Important reasons for poor health for African Americans, more commonly referred to as the “slave health deficit” are deeply intertwined with and stem from the previous examples of racist medicine and other medically egregious acts against black people. For too many blacks, the knowledge of these medical experiments and many others not discussed in this essay leave an indelible mark of mistrust, fear, and suspicion towards the health care system and its health care providers. Although Title VI of the 1964 Civil Right Act sought to rectify the legacy of racist medicine, many blacks today continue to perceive racial discrimination and medical neglect by health care providers; they refuse to visit a provider to seek primary care, diagnostic screening, or lingering health concerns. Unfortunately, this Civil Rights Act left open too many opportunities for medical researchers and health care providers to continue to participate in unethical behaviors such

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<sup>12</sup> Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York, New York, Pantheon Books, 1997), 90.

as forced sterilizations on black women as noted above, unnecessary surgeries, medical experimentation, and inadequate health care.

More contemporarily, the 2003 Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, convened by the Institute of Medicine in Washington, D.C.,<sup>13</sup> unveiled and reported continual unethical behavior in health care that is connected with racial and ethnic bias and stereotyping. For example, in medical or clinical decision-making, even when patients are black and medically insured, some health care providers do not order the necessary diagnostic and screening tests to rule out a patient's chief complaint. Reportedly, some providers, "give an untreatable diagnosis to a patient, or order limited treatments, or deny radiation or chemotherapy for cancer, dialysis for kidney failure, and bypass or balloon surgery and a pacemaker for heart disease cases."<sup>14</sup> As a result of insufficient health care too many black people continue to become sicker and sicker. A code black alarm needs to ring loudly, signifying an emergency to save human lives, especially from preventable and curable diseases that lead to black peoples' highly disproportionate rates of morbidity and mortality.

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<sup>13</sup> See Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, D.C.: The National Academies Press, 2003), 102.

<sup>14</sup> Emilie M. Townes, *Breaking the Fine Rain of Death: African American Health Issues and a Womanist Ethic of Care* (New York, New York: Continuum Publishing Company, 1998), 117-8.

The January 2005 issue of *Morbidity and Mortality Weekly*, in particular, reveals that blacks continue to have highly disproportionate rates of medical and public health problems such as: various types of cancers, HIV/AIDS and other sexually transmitted infections, obesity, cardiovascular diseases, strokes, diabetes, hypertension, infant mortality, childhood asthma, unintentional accidents, homicides, and other health concerns. These serious health concerns may potentially lead to premature deaths, decreased quality of life, loss of economic opportunities, and ongoing mistrust of the health care system. Many black people might ponder this question: why trust physicians or medical researchers whom they perceive as violent, racist, non-caring, and abusive all because of their dark skin color, myths about their inferior mental status, and their Constitutional designation as 3/5<sup>th</sup> of a person?

A government-appointed commission comprised of philosophers, theologians, lawyers, physicians, nurses, etc. was charged with bringing some resolution to the human research and medical abuse, especially in light of the public disclosure of the Tuskegee Syphilis Study. It was thought that perhaps the commissioners' collaborative efforts to develop and implement the 1979 *Belmont Report*<sup>15</sup> would bring huge

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<sup>15</sup> It is important to know that there were three primary documents that provide the foundation for efforts to protect human beings who participate in research: The *Nuremberg Code*, the *Declaration of Helsinki* and the *Belmont Report*. The *Nuremberg Code* is a statement on medical ethics that was issued in 1947 after the trial of 23 medical doctors accused of atrocities committed during the Nazi era in Europe in World War II. The *Declaration of Helsinki* on Ethical principle for Medical Research

resolutions and an end to the history of medical abuse and neglect. It is very unfortunate that this report does not address directly the health care system that is built on racist and egregious acts against black people. Instead the commissioners decided on a report that would focus on modern secular bioethics which is undergirded by Western European philosophical theories and four mid-level principles, both of which are intrinsic to an American liberal philosophy of justice. These theories and principles do not challenge institutionalized racism, white privilege, nor do they acknowledge the misuse and abuse of many black peoples' bodies for the development of American medicine and research.

### **The Influence of the 1979 *Belmont Report* on the Black Health Crisis**

Public disclosure of the Tuskegee Syphilis Study prompted the need for government intervention to establish ethical principles and guidelines for the protection of human subject research. For example, on July 12, 1974, the National Research Act (Pub L. 93-348) was signed into law, which, in turn, established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. One of the responsibilities of the National Commission was to identify the basic ethical principles that should underline the conduct of biomedical and behavioral research involving

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Involving Human Subjects was adopted by the World Medical Association (WMA) in its 18<sup>th</sup> General assembly in Helsinki, Finland in 1964. The *Belmont Report* is the one discussed in detail in this paper.

human subjects and to develop guidelines which should be followed to assure that such research is conducted in accordance with those principles.

After four years of deliberation, the commissioners published the *Belmont Report* which contained a detailed discussion of the four mid-level principles of bioethics: respect for person/autonomy, beneficence, non-maleficence, and justice.<sup>16</sup> They are mid-level principles because they were deduced from universal Western philosophical theories such as utilitarianism, Kantian deontology or the categorical imperative, egalitarianism, social contract theory, and libertarianism. The mid-level principles are believed “to be objective, rational, internally coherent, and consistent, universally applicable, detached from individual self-interest, and impersonal in their capacity to transcend the particularities of time and culture.”<sup>17</sup> Extremely important to the *Belmont Report*, the four principles of bioethics are to be employed judiciously to prevent research and clinical practice abuses while treating everyone the same regardless of race, class, gender, creed, or national origin. The principles supposedly allow for a systematized way for prescriptive as opposed to descriptive judgments to be made in the ethical decision-making process.

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<sup>16</sup> Albert Jonsen, “On the Origins and Future of the Belmont Report,” 3-12.

<sup>17</sup> Daniel Callahan, “Universalism & Particularism: Fighting to a Draw.” *The Hasting Center Report* 30 (January/February 2000): 40.

Often referred to as the principle of *autonomy*, respect for persons is the first principle of biomedical ethics. An autonomous individual is a free, independent, rational thinking, self-ruled individual who makes choices and decisions without external influence or force. Autonomy as it applies to research and the clinic process means that the free human person is the main focus of moral concern. Key to this principle is always the notion of a personal or individual freedom. To be autonomous requires that an individual understands correctly and clearly what is proposed. For example, in a research protocol or a clinical procedure after it is explained, one discerns whether or not to participate.<sup>18</sup>

Next, the principle of *beneficence* requires that human beings not only respect individual autonomy, but to do good (benevolence) by contributing to the well-being of persons.<sup>19</sup> Unlike the principle of respect for persons, this principle entails an obligation by the health care provider to protect persons from harm by maximizing anticipated benefits and minimizing possible risks of harm or burdens.

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<sup>18</sup> Other words associated with autonomy include: individual choice, liberty rights, self-rule, freedom of the will, privacy, and self-government. Those who have diminished decisional capacity may need someone else to decide for them, which diminishes their autonomy. In this respect, these individuals are controlled by another's decisions, which Kant would claim is not autonomy but heteronomy.

<sup>19</sup> James Childress and Tom Beauchamp, *Principles of Bioethics*, (Washington, D.C.: Georgetown University, 1994), 259.

The principle of *non-maleficence* means that harm must not be caused intentionally. Although it has long roots that extend back to the Hippocratic Oath tradition and also is found in tenets of the Ten Commandments or the *Decalogue*,<sup>20</sup> it was a later addition to the initial three principles of bioethics. This principle has both secular and theological underpinnings. It is unethical to intentionally harm another.

Finally, the principle of *justice* defines what it means to treat others equitably or fairly. “The primary question raised with respect to the principle of justice is: who ought to receive the benefits of research and bear its burdens?”<sup>21</sup> This is a critically important question given the ethos of rugged individualism, white privilege, racism, capitalism, and the marginalization of the least fortunate, economically poor, or the working poor in our U.S. society.

In essence, the commissioners appeared to have established a win-win situation for patients/clients/research subjects alike in tandem with health care providers, or medical researchers. A main objective of the patient-physician relationship is that patient/client individual human rights are

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<sup>20</sup> Here the *Decalogue* refers to Ten Commandments, or a series of ten laws found in the Book of Exodus (20:2-11) and Deuteronomy (5:6-15).

<sup>21</sup> See materials from the *Belmont Report 25<sup>th</sup> Anniversary Symposium and Webcast*, May 14, 2004, Medical College of Wisconsin. The event commemorates the 25<sup>th</sup> anniversary of the *Belmont Report* by reuniting key authors, staff, and the remaining members of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.



guaranteed, while the four principles of bioethics remain at the forefront of the relationship.

Theological ethicist Cheryl J. Sanders recognizes the major use of these aforementioned four principles especially as they are embedded into the fabric of our American ethos. For Sanders, “[o]ne of the most significant contributions thinkers of European and European-American descent have made to the field of bioethics is drawing on these ethical principles to make applications to a broad range of problems and cases.”<sup>22</sup> However, Sanders critiques, “the apparent marginalization of race [in the development of these principles] indicates a devaluation of the [African American] community and belief systems characteristic of African American ethical discourse and social life.”<sup>23</sup> Mindful that the *Belmont Report* was published seven years after the 1972 public disclosure of the Tuskegee Syphilis Study, its point of departure is not the socioeconomically poor and uneducated black men of this study, which speaks volumes about what normative bioethics is in USA society. Rather its point of departure includes principles based in a European and European-American ethos that tends to disregard the type of particularity that is characteristic of these socioeconomically poor and uneducated black men.

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<sup>22</sup> Cheryl J. Sanders, “European-American Ethos and Principlism: An African-American Challenge,” in *A Matter of Principles? Ferment in U.S. Bioethics*, ed. Edwin R. DuBose, Ronald P. Hamel, and Laurence J. O’Connell (Valley Forge, Pennsylvania: Trinity Press International, 1994), 148-63, esp. 148.

<sup>23</sup> *Ibid.*, 148.

The principles are to be applied universally and presumed to be cross-culturally inclusive in secular moral ethics. Sanders declares that these principles tend to be “dualistic, exclusive, individualistic, secular, atheistic, inflexible, materialistic and harbor the necessary and sufficient conditions for the propagation of racism.”<sup>24</sup> Bioethicist Annette Dula echoes Sanders’ critique. She further notes that “inattention to cultural and societal aspects of health care may be attributed in part to the mainstream Western philosophical theories and principles. Furthermore, these theories and principles presented primarily as a thinking enterprise in bioethics are rarely used to advocate for change, social justice, or societal transformation.”<sup>25</sup>

Hence, by ignoring the relevant features of the men who participated in the Tuskegee Syphilis Study, arguably, the commissioners charged with the development of the *Belmont Report* failed to protect *all* human subjects in a holistic manner. The vulnerable research subjects of the Tuskegee Syphilis Study were deceived and coerced into participating in the forty-year study that investigated the progression of syphilis. Because of their race and socioeconomic status, United States Public Health Services researchers preyed on these men’s presumed intellectual inferiority and

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<sup>24</sup> Cheryl J. Sanders, “European-Americans and Principlism,” 151.

<sup>25</sup> Annette Dula, “Toward an African-American Perspective on Bioethics,” *Cross Cultural Perspectives in Medical Ethics, 2<sup>nd</sup> Edition*, ed. Robert M. Veatch (Sudbury, Massachusetts: Jones and Bartlett Publishers, 2000), 357-69, esp. 360.

economically impoverished state and therefore, saw no need to include in the research protocol ways to seek a deeper understanding of the social, economic, and political experiences that shaped their life's history. These poor black men were deemed expendable and were used and abused for the researchers' professional development and self-aggrandizement.

According to physician and bioethicist Edmund D. Pellegrino in order

[t]o understand the moment and direction of moral decisions in any person's life, we need as much knowledge as possible of the internal and external forces that have shaped that person's life's history. A clinical case history or a moral dilemma is always part of a larger life story, an act or a scene in the complex drama of life.<sup>26</sup>

For example, the African American ethos, which is largely derived from traditional African cultures, is essentially holistic, inclusive, communalistic, spiritual, theistic, improvisational, and humanistic in many ways that the European-American ethos is not."<sup>27</sup> The commissioners' use of the impartial, universal, secular, and so-called all-encompassing principles allowed them to miss a full-blown discussion on how white racism works in the medical abuse

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<sup>26</sup> Edmund D. Pellegrino, "Bioethics at Century's Turn: Can Normative Ethics be Retrieved?" *Journal of Medicine and Philosophy* 25 (2000): 664.

<sup>27</sup> *Ibid.*, 151.

and maltreatment of these men. Instead they embraced the ‘normativity of whiteness’<sup>28</sup> in the mere employment of these four principles.

Philosopher Cornel West writes of this concern also, while challenging white philosophers to face up to the historic and current implications of mainly focusing in on the works of white thinkers.<sup>29</sup> He observes that these [Western European philosophies] were used strategically to “promote black inferiority and constituted the European background which suppressed black diasporan struggles for identity, dignity (self-confidence, self-respect, self-esteem).”<sup>30</sup> Furthermore, bioethicist and anthropologist Catherine Myser notes that the use of these universal philosophies fosters a lack of attention to difference (i.e., of the research participants) and promotes white supremacist privilege,<sup>31</sup> reflective of the Tuskegee Syphilis Study’s principle investigators from the United States Public Health Department. One must ask if employing these

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<sup>28</sup> Catherine Myser, “Difference from Somewhere: The Normativity of Whiteness in Bioethics in the United States.” *American Journal of Bioethics* 3 (2003): 1-11.

<sup>29</sup> Cornel West, “Race and Modernity,” in *The Cornel West Reader* (New York, New York: Basic Civitas Books, 1999), 55-86.

<sup>30</sup> Cornel West, “The New Cultural Politics of Difference,” in *The Cornel West Reader* (New York, New York: Basic Civitas Books, 1999), 119-39, esp. 128.

<sup>31</sup> Catherine Myser, “Difference from Somewhere: The Normativity of Whiteness in Bioethics in the United States.” *American Journal of Bioethics* 3 (2003): 1.

principles has something to do with continuing racist medicine and many blacks' perceived racial discrimination. Is there a link between the theories and principles to the persistent black health crisis in the United States? When is a 'code black' going to sound to address the black health crisis that is undergirded by a racist medicine, and the long history of black exploitation and abuse in medical research and the clinical setting?

Since the *Belmont Report* seemingly did nothing directly to address the particular social location of the black research participants of the Tuskegee Syphilis Study, arguably, one can make the case that this infamous study remains linked to many of blacks' deep-seated attitudes of distrust, suspicion, and fear of health care providers and medical institutions in the United States.<sup>32</sup> This is despite the fact that medical facilities and health care providers are regulated by local and federal governmental standards and codes of ethics. Today "the federal government has been shown more likely to close down entire university research programs under the aegis of the Federal Drug Administration (FDA) when embarrassed by federally sponsored abuse."<sup>33</sup> All standards and codes were created to ensure human protection from any medical abuse—

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<sup>32</sup> Peter A. Clark, "Prejudice and the Medical Profession: Racism, Sometimes Overt, Sometimes Subtle, Continues to Plague U.S. Health Care." *Health Progress* 84 (September 2003): 12-23.

<sup>33</sup> Harriet A. Washington, *Medical Apartheid*, 388.

research, academic, and/or clinical.<sup>34</sup> For the standards and codes, the individual patient or client is of most importance; they must be protected from medical harm. Individuals have the right to make informed decisions or give informed consent to undergo health care screenings, diagnosis, and/or treatments.

Still too many blacks remain afraid, carry negative attitudes, and are reluctant to engage the health care system. Too many perceive racial discrimination by health care providers and do not want to be bothered with them. Their dispositions lead to reasons for the high rates of black morbidity and mortality. Indeed a need exists for black people to move from so much paralyzing fear, anger, suspicion, and mistrust of health care providers in the health care system to a greater ability to engage in self-care, self-love, to have high self-esteem, and to be self-empowered persons. Today a need exists for health care providers and medical researchers to acknowledge the horrible history of black medical abuse and neglect, but a need also exists for black people to regain trust in the health care system that, for the most part, is very responsive to the code black alarm.

I offer that the Catholic Church in black communities, especially, has a major role to play in helping to liberate the ailing captives by focusing on health promotion and primary prevention. What does a black Catholic liberation bioethics

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<sup>34</sup> J. Wasserman, M.A. Flannery, and J.M. Clair, "Raising the Ivory Tower: The Production of Knowledge and Distrust of Medicine among African Americans." *Journal of Medical Ethics* 33 (2007):177-80.

have to offer in addressing the black health crisis in this country? What does a black Catholic liberation bioethics have to offer to shore up the deficiencies of principles derived from Western European philosophical thought?

### **A Black Catholic Liberation Bioethics**

I am defining a Black Catholic liberation bioethics as it not only transcends or moves beyond mainstream secular bioethical theories and principles but it means that Christians must do the will of God as modeled in the liberating Gospel of Jesus Christ. That will is in the context of communal relationships (or as I will later discuss, lay health advocates) that seek the realization of the wholeness of life despite egregious unethical acts done unto black bodies and black lives in clinical medicine and scientific research. “That wholeness of life embraces the total existence of human life in the past; it embraces the total meaning of black *being* with regard to the past, present, and future.”<sup>35</sup> A black Catholic liberation bioethics is also reconciling and liberating. Reconciliation and liberation <sup>36</sup> underscore hope for healing

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<sup>35</sup> Allan Aubrey Boesak, *Farewell to Innocence: A Socio-Ethical Study on Black Theology and Black Power* (Maryknoll, New York: Orbis Books, 1977), 141.

<sup>36</sup> Dwight Hopkins, *Introducing Black Theology of Liberation* (Maryknoll, New York, Orbis Books, 1999), 62-3. It is important to note that, traditionally, within the black political theology trend, Cone will come to reconciliation after a redistribution of white political power. Roberts, in contrast, stands for black liberation against white racism and, simultaneously, for genuine reconciliation with white people. He targets liberation and reconciliation as the “twin goals” and “two main poles” of

and freedom of black people from the memory and experience of egregious unethical medical acts. One method of critically examining the wholeness of black human life in tandem with reconciliation and liberation is through the pastoral circle.

The pastoral circle is a three-part social analytical process, including: *seeing*, *judging*, and *acting*. I am adding the need for *understanding* between seeing and judging in this circle, lest we prejudge too quickly, starting to analyze and make decisions about the situation only after we see. In the acting part, I propose the notion of a ministry of accompaniment for black patients/clients via the use of lay health advocates.

The pastoral circle allows one to *see* that clinical medicine and scientific research in the United States has not been the most respectful of black bodies or black lives. The memory of it persists today and is manifested in fear and mistrust of the health care system. As aforementioned, health statistics reveal that blacks continue to be adversely affected

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black theology. Liberation calls for black people's freedom from the bondage of white racism. And reconciliation suggests that black freedom does not deny white humanity but meets whiteness on equal ground. Roberts seeks to develop both goals in a balanced way: that is, in terms of (1) always explaining one in relation to the other, and (2) using them as the core ground which he weaves his systematic theology. I am using these terms: Reconciliation and Liberation in the context of bioethics—healing and freedom of black people from the memory and experience of egregious unethical acts. It takes two to continue to dance of the oppressor and oppressed relationship and both need to be reconciled and liberated to stop the continuous dysfunctional dance.



by the slave health deficit or black health crisis. Empirical data on health reveals that overall black people experience highly disproportionate rates of preventable and treatable diseases such as diabetes, hypertension, stroke, breast and prostate cancer, mental illness, problems from illegal drug use and alcoholism, HIV/AIDS and STI's, among others. Electively induced abortions and homicides occur at a disproportionately high rate too. A huge ethical issue for anyone concerned is that the black population rate is not growing consistently, rapidly, and exponentially upward as other U.S. populations are. Aware of this data, one must not find it difficult to ponder and to ask, are black people in danger of extinction or how close is it to the full extermination of this population? What must be done to increase the population growth rate in this group?

Before moving on to judging the empirical data, one must *understand* that despite abuse, exploitation, and mistreatment, for centuries, black people 'got over,' making a way out of no way through faith in the Jesus Christ, the Liberator. For theologian J. Deotis Roberts this is because

[O]urs has been a hope against hope. Indeed, for us, faith has been the substance of things hoped for. It has been based upon unseen evidence...The black faithful knows what it means to reach out into the darkness and grasp the hand of God, to take a step at a time in the shadows and to find

such trust better than light, better than a well-trodden path.<sup>37</sup>

They understand that deep down inside that God did not make junk; that God created everyone and everything good not to be used and abused by another.

A *judgment* can be made on the three broadly construed aforementioned accounts: first, members of the national commission who developed the 1979 *Belmont Report* missed a great opportunity to recall the long history of medical abuse and maltreatment in the black population, and to delineate a plan that addressed how to eradicate or dismantle racism instantly in the health care and medical research system. Secondly, black people continue to perceive racial discrimination in the health care provider and patient/client relationship despite professional ethical codes and standards, patients' bill of rights, the process of informed consent, the four principles of bioethics, etc. Various types of professional journal articles and books report that still many black people do not receive the same kind of medical treatment as their white counterparts even when black people have the appropriate medical insurance. This information does not assist in remedying black people's perceived racial discrimination. Rather, this perception seems to be perpetuated consciously or unconsciously by them with no clear end in sight. Thirdly, many black people today lack the financial, mental, and/or physical ability to engage in primary

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<sup>37</sup> J. Deotis Roberts, *A Black Political Theology* (Louisville, Kentucky: John Knox Press, 1974), 64.

prevention and health promotion. They hold onto deeply embedded fear, mistrust, and suspicion of the health care system and their providers. Many are unemployed or underemployed and, therefore, lack adequate health insurance or are completely uninsured. These three accounts require actions that significantly decrease the health crisis in black communities across the United States. Again, a *code black alarm* needs to be called, generating a *black Catholic liberation bioethics*.

A concrete *action* that I offer in putting into practice a black Catholic liberation bioethics is to train lay health advocates who are attentive, intelligent, rational, and responsible about this emergency in black health. Characteristically, lay health advocates must strongly desire to assist in finding a resolution to the problems and barriers to black health care in tandem with championing primary care prevention and health promotion. This idea of lay health advocates comes from my thinking about the notion of medical foster parents for children, although there are many differences. Medical foster parents, for example, assist critically ill children because the parents for whatever reasons are not able to follow through with the necessary and demanding medical regiment that the child needs in order to improve or recover from his/her illness. Medical foster parents work closely with the biological parents and child to get the child's health needs addressed adequately and in a timely manner.

Nevertheless, lay health advocates must feel a deep sense of urgency while they respond to a code black, and/or while

promoting a culture of life. Through an intensive formation process they are trained to come to the rescue. Acknowledging the time and dedication needed for this ministry training and formation, their ministry as lay health advocates is to offer a peaceful, pastoral, and prayerful presence as they accompany the patient/client in his/her health care situation. These advocates understand what it means to be a part of a sacred trust because “to be a Christian is to live as part of a body and the parts need always to be developing their relationships with one another.”<sup>38</sup>

Ultimately, they become very adept at journeying in a mutual and respectful way with the patient/client: in communicating with the medical professionals, in negotiating bureaucratic health insurance companies, in following up with medical concerns or referrals, in helping to discuss and to organize prescription medications, among many other areas. In addition, lay health advocates are not afraid to explore further options for health care with the patient/client, or assist in obtaining second opinions with the patient/client. In essence, they embrace and live out the words of the Lukan Jesus in Luke 4: 18-19:

“The spirit of the Lord is upon me, because he has chosen me to bring good news to the poor. He has sent me to proclaim liberty to the captives and recovery of sight to the blind, to set free the

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<sup>38</sup> Barbara J. Blodgett, *Lives Entrusted: An Ethic of Trust for Ministry* (Minneapolis, MN: Fortress Press, 2008), 1.

oppressed and announce that the time has come when the Lord will save his people.”

Ultimately, the goal of the lay health advocate and the patients/clients is to respond to the code black alarm so as to help in the realization of a black Catholic liberation bioethics through a ministry of accompaniment.

### **Summary and Conclusion**

In this paper, I attempted to look at the crisis in black health that has a long history extending back to the Antebellum Period. The public disclosure of the forty-year Tuskegee Syphilis Study provoked the United States Government to appoint a national commission to establish ethical guidelines for research on human subjects contained in the *1979 Belmont Report*. These guidelines include the four principles of bioethics that were derived from Western European philosophies or normative ethical theories. In a close examination of this ethical system in which mainstream bioethics is built, I critiqued the fact that these ethical theories and principles promote what Catherine Myser ‘a lack of attention to difference.’ Further, historically, Western European philosophies were used strategically to promote black inferiority and constituted the European background which suppressed black diasporan struggles for identity and dignity (self-confidence, self-respect, and self-esteem). I argued that the use of these philosophies and principles ignore the long history of unethical medical treatment of black people in the American health care system and medical research institutions. The commissioners missed an opportunity to

acknowledge that American health care is a racist institution. An emergency black health crisis continues today and that the onus is on members of black communities and others of good will to respond creatively and concretely to address the dire health problems facing this population. I stressed that a code black alarm has been ringing loudly for years, indeed centuries and that people need to come to the rescue immediately before the black population vanishes. I suggest that the emergency black health crisis can be addressed through a ministry of accompaniment program that includes lay health advocates who are sold on the idea of a black Catholic liberation bioethics. Through extensive training and formation they make a formal commitment to journey mutually, responsibly, and respectfully with patients and clients who need assistance navigating the complex health care system, and in helping them to understand the need for health promotion and primary care prevention. In essence, these lay health advocates are trained to respond to the code black alarm, in light of a black Catholic liberation bioethics.

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