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Code Black: Theological Bioethics on the Black Health Care Crisis in the United States [1]

Author and Presenter:

Shawnee M. Daniels-Sykes, SSND, Ph.D, Adjunct Assistant Professor Institute for Black Catholic Studies, Assistant Professor, Mount Mary College Department of Theology, Milwaukee, Wisconsin.

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).

Entitled, *Code Black: Theological Bioethics on the Black Health Care Crisis in the United States,* 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 a few of the many reasons for the black

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health crisis in the USA. 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.[2]

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 care. The code calls forth lay health advocates to offer assistance to patients and clients 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 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 thinking about and writing on this topic from a theological bioethical perspective, especially as I critique secular bioethical theories and principles.

Black people hail from a culture of deep religious and spiritual roots; they have found meaning in pain and suffering, especially through the black spirituals, prayers, and reflection of the mission and ministry of Jesus as revealed in the Gospel message. Even though, a purely modern secular bioethical approach has been used to evaluate all ethical concerns related to human life, I maintain that this is not sufficient enough to assist Black people in making ethical decisions about beginning of life issues, in the middle of life issues, and end of life issues,

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[2] Diana J. Burgess, Yingmei Ding, Margaret Hargroves, Michele van Ryn, Sean Phelan, *Journal of Health Care for the Poor and Underserved* 19 (2008): 895.

otherwise I think that we would not be so inundated with such an extreme crisis in black health care. Today we find ourselves in a culture of death instead of a culture of life. In order to move beyond the impasse of the black health care crisis we must renew or revive our embrace of the God of justice and love, engage in right action instead of passive-aggression and strive vigorously toward liberation, reconciliation, peacefulness, community, trust, honesty, authenticity, a listening heart, and great communication skills. A tireless ability to negotiate the health care system is essential as I am proposing that lay health advocates assist patients in responding proactively to significant health issues and access to health care. Constant are prayers and actions toward freedom from oppression, depression, anger, and anxiety, including the elimination of our dysfunctional dance between white racism and black self-hatred. Even though racism, sexism, and classism are embedded in the fabric of the institution of health care in the United States, we are challenged as members of the black community to move out of a victim stance to one that embraces black self-empowerment, black self-esteem, black self-care, and black self-love. We must learn to cope directly with the 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. We must trust that health care and access to it is about human dignity and human flourishing and we have a mandate, indeed an obligation to take great care of ourselves mentally, spiritually, physiologically, and physically.

In this paper, I argue that theological bioethics has something profound to say in contrast to the U.S. Government's promulgation of the July 1979 *Belmont Report*,[3] the latter, which includes ethical principles derived from Western European philosophies employed for the

[3] Albert Jonsen, "On the Origins and Future of the Belmont Report," (Pages 3-12), 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).

protection of human subjects of research. These principles, which will be discussed later on in this paper, ignore the long history of unethical medical treatment of black people in the American health care system and medical research institutions.

To develop my argument, I propose: 1) to present a brief overview of the history of medical abuse of black people by members of US medical and research establishments; 2) to discuss and critique 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, 3) to explore what theological bioethics means in light of the health care crisis in the black community as we move beyond what Carmelite Constance Fitzgerald calls, 'impasse and dark night,'[4] and finally, 4) to begin a discussion on what I am calling the ministry of accompaniment, which involves a ministry of lay health advocates who are in relationship with patients/clients navigating the complex and complicated health care system in the United States.

Overview of Blacks Experiences in Health Care

Since the time of African chattel slavery, blacks have been the subjects of research and medical abuse. According to bioethicist and journalist Harriet A. Washington, "[e]slavement 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

[4] Constance Fitzgerald, "Impasse and Dark Night," http://www.baltimorecarmel.org/saints/john%20of%20the%20Cross/impasse%20and%20 downloaded March 16, 2009.

bolstered physicians' professional advancement."[5] The poem, *The Dissecting Hall* illustrates further this notion about "clinical material,"

> Yuh see dat house? Dat great brick house? Way younder down the street?
> Dey used to take dead folk een dar wrapped een a long white sheet.
> An' sometimes we'en a nigger'd stopped, a-wondering who was dead.
> Dem stujent men would take a club an' bat 'im on de head.
> An' drag dat poor dead nigger chile right een dat 'section hall to vestigate
> 'is liver—lights—
> His gizzard an' 'is gall.
> Tek off dat nigger's han's an'feet—
> His eyes, his head, an 'all, an' w'en dem stujent finish Dar was nothin' left at all.[6]

Blacks during the Antebellum Period had little control over medical decisions made to use their bodies or even to use their corpses for medical research.[7] 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.[8] To the contrary, Blacks had the smallest skulls, the smallest brains, and were thus, considered unintelligent with no character.[9]

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

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[5] 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.

[6] This conversation was found in an article by Tod 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 t he source to verify the conversation.

[7] Todd L. Savitt, "The Use of Blacks for Medical Experimentation and Demonstration in the Old South," *Journal of Southern History* 48 (August 1982): 331-48.

[8] Harriet A. Washington, *Medical Apartheid,* 35

[9] *Ibid.*, 35.

procedure.[10] 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 against typhoid infection that resulted from his successful experimentation on thirty slaves and free blacks.[11]

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 cell-line, or HeLa cells.[12]

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.

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[10] 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,* pages 263-300 (Ann Arbor, Michigan: University of Michigan Press, 2002).

[11] Barbara L. Bernier, "Class, Race, and Poverty: Medical Technologies and Socio-Political Choices," *Harvard Blackletter Law Journal* 115 (1994): 119.

[12] 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.

Whether in the experimental or control group, the human rights and dignity of 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."[13] In addition, some women would enter the hospital to have a baby and for unknown reasons they would end up having a Cesarean Section performed, which included sterilization.

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 unethical 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 racism in medicine, many blacks today continue to perceive racial discrimination and medical neglect by health care providers; they refused 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 as forced sterilizations on black women as noted above, unnecessary surgeries, medical experimentation, and inadequate health care.

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[13] Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York, New York, Pantheon Books, 1997), 90.

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.,[14] 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."[15] 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.

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, mental illness, cardiovascular diseases, stokes, diabetes, hypertension, infant mortality, childhood asthma, unintentional accidents, gun violence, homicides, and other health concerns. It is important to note here that today there is a resurgence of syphilis in black communities. Found in a highly disproportionate rate in our communities, primary and secondary syphilis leave open sores on the skin surrounding the genital areas which act as portals for the rapid

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[14] See Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, D.C.: The National Academies Press, 2003). 102.

[15] Emilie M. Townes, *Breaking the Fine Rain of Death: African American Health Issues and a Womanist Ethics of Care* (New York, New York: Continuum Publishing Company, 1998), 117-8.

transmission of the virus that causes AIDS. Nonetheless, serious health concerns may potentially lead to premature deaths, high infant mortality rates, decreased quality of life, loss of economic opportunities, and ongoing mistrust and suspicion 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 $3/5^{th}$ of a person? Why trust an American health care system that is based on racist medicine?

A government appointed commission comprised of philosophers, theologians, lawyers, physicians, nurses, etc. were charged with bringing some resolution to human research and medical abuses, especially in light of the public disclosure of the Tuskegee Syphilis Study. It was thought that perhaps the commissioners' collaborative and interdisciplinary efforts to develop the 1979 *Belmont Report*[16] would bring huge resolutions and an end to the history of medical abuse and neglect in the United States. 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 which are inherent 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

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

American medicine and research. Rather they promote a moral universalism (i.e., prescriptive ethics) instead of a moral particularism (i.e., descriptive ethics) that is attentive to race, class, age, and gender, diversity, for example.

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 subjects of 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 identity the basic ethical principles that should underline the conduct of biomedical and behavioral research involving 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, beneficience, non-maleficence, and justice.[17] These mid-level principles were deduced from universal Western philosophical theories such as John Stuart Mill's utilitarianism, Immanuel Kant's deontology or the categorical imperative, John Rawls' egalitarianism and social contract theory, and Robert Nozick's libertarianism. Arguably, these theories and principles are "objective, rational, internally coherent, and consistent, universally applicable, detached from individual self-interest, and impersonal in their capacity to transcend the

[17] Albert Jonsen, "On the Origins and Future of the Belmont Report," 3-12.

particularities of time and culture."[18] 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. These principles, which supposedly transcend or ignore particular cultures, histories, and time are based in normative whiteness and allow for a systematized way for prescriptive as opposed to descriptive judgments to be made in the ethical decision-making process.

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 clinical patient/client physician relationship means that the free human being is a human person. That the human being who is a human person who has moral agency or the ability to choose to do whatever she or he desires without external force or coercion. Key to this principle is always the notion of personal or individual freedoms/rights. 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 give her/his informed consent.[19] In addition, a fetus is a human being, but not a human person.

[18] Daniel Callahan, "Universalism & Particularism: Fighting to a Draw, "*The Hasting Center Report* 30 (January/February 2000): 40.

[19] 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 some one else to decide for them, which diminished their autonomy. In this respect, these individual are controlled by another's decisions, which Kant would claim is not autonomy but heteronomy.

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.[20] 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. Still the health care provider or medical research scientist has personal or individual freedoms/rights to choose to do whatever she or he desires. She or he has no obligation to accept patients who carry Title XIX or Medicaid or who are medically underinsured or uninsured.

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*,[21] it was a later addition to the initial three principles of bioethics. This principle has both secular and theological underpinnings. In essence, 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?"[22] This is a critically important question given the ethos of rugged individualism, white privilege, racism, capitalism, and the marginalization of the

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[20] James Childress and Tom Beauchamp, *Principles of Bioethics*, (Washington, D.C.: Georgetown University, 1994), 259

[21] 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).

[22] See materials from the *Belmont Report 25th Anniversary Symposium and Webcast*, May 14, 2004, Medical College of Wisconsin. The event commemorates the 25th 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.

least fortunate, economically poor, or the working poor in our U.S. society. The Western European philosophical theories, which are embedded in the fabric of the U.S. health care delivery system supports individual justice as opposed to social justice.

Arguably, 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. Two main objectives of the patient-physician relationship are that 1.) the patient/client individual human rights and human dignity are guaranteed and 2.) the patient/client is getting the necessary medical attention. The four principles of bioethics remain at the forefront of that relationship.

Theological ethicist Cheryl J. Sanders recognizes the major use of the aforementioned four principles of bioethics, 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."[23] However, Sanders critiques, "the apparent marginalization of race [in the development of these principles] which indicates a devaluation of the [African American] community and belief systems characteristic of African American ethical discourse and social life.[24] 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 normative bioethics that coheres with an American liberal philosophy of

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[23] Cheryl J. Sanders, "European-Americans Ethos and Principlism: An African-American Challenge," page 148, in *A Matter of Principles? Ferment in U.S. Bioethics* edited by Edwin R. DuBose, Ronald P. Hamel, and Laurence J. O'Connell, (Valley Forge, Pennsylvania: Trinity Press International, 1994), 148-63.

[24] *Ibid.,* 148.

justice. Its points of departure champion principles based in a European and European-American ethos that tends to disregard the type of moral particularity that is characteristic of these socioeconomically poor, vulnerable, and uneducated black men of the Tuskegee Syphilis Study.

Sanders also observes 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."[25] Bioethicist Annette Dula echoes Sanders' critique. She further notes that "inattention to cultural and societal aspects of health care must 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.[26]

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 long study that investigated the progression of syphilis. Because of their race, gender, and socioeconomic status, the United States Public Health Services researchers preyed on these men's presumed intellectual inferiority and economically impoverished state and therefore, saw no need to include in the research protocol ways to seek a deeper understanding of the social, economic, political, and theological experiences that shaped their life's history. These poor black

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[25] Cheryl J. Sanders, "European-Americans and Principlism, 151.

[26] Annette Dula, "Toward an African-American Perspective on Bioethics," pages 357-69 , in Robert M. Veatch *Cross Cultural Perspectives in Medical Ethics,* 2nd Edition (Sudbury, Massachusetts: Jones and Bartlett Publishers, 2000), 360

men were deemed expendable and were used and abused for the researchers' professional development and self-aggrandizement.

According to physician and bioethicist Edmund D. Pelligrino 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.[27]

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."[28] 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 or white supremacy operated covertly and overtly in the medical abuse and maltreatment of these men. Instead the commissioners embraced what bioethicist Catherine Myser calls the 'normativity of whiteness'[29] in the mere employment of these four principles. Furthermore, she observes 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,[30] reminiscent of the Tuskegee Syphilis Study's principle investigators' attitudes and behaviors.

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[27] Edmund D. Pelligrino, "Bioethics at Century's Turn: Can Normative Ethics be Retrieved?" *Journal of Medicine and Philosophy* 25 (2000): 664.

[28] *Ibid.,* 151.

[29] Catherine Myser, "Difference from Somewhere: The Normativity of Whiteness in Bioethics in the United States," *American Journal of Bioethics* 3(2003): 1-11.

[30] Catherine Myser, "Difference from Somewhere: The Normativity of Whiteness in Bioethics in the United States," *American Journal of Bioethics* 3 (2003): 1

Philosopher Cornel West writes about his concerns also, while challenging white philosophers to face up to the historic and current implications of mainly focusing in on the works of white thinkers.[31] 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)."[32] One must ask if employing these principles has something to do with continuing racist medicine and many blacks' perceived racial discrimination. Given that there is 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 care crisis that is undergirded by racist medicine, as well as a 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.[33] 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

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[31] See Cornel West, "Race and Modernity," pages 55-86 in *The Cornel West Reader* (New York, New York: Basic *Civitas* Books, 1999).

[32] Cornel West, "The New Cultural Politics of Difference," Pages 119-39. In *The Cornel West Reader* (New York, New York: Basic *Civitas* Books, 1999), 128.

[33] See 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.

the Federal Drug Administration (FDA) when embarrassed by federally sponsored abuse."[34] All standards and codes were created to ensure human protection from any medical abuse—research, academic, and/or clinical.[35] For the standards and codes, the individual patient or client is of most importance; they must be protected from medical non-maleficience. Individuals have the right to make informed decisions or give informed consent to undergo health care screenings, diagnosis, and/or treatments.

So, if these standards and codes are of overarching importance, then why is it that still too many blacks remain afraid, carry negative attitudes, and are reluctant to engage the health care system? Do they know and understand that safeguards exist for the protection of patients/clients or research subjects? Still too many black people perceive and experience racial discrimination by health care providers and would rather not be bothered with them and the health care delivery system. Their dispositions lead to reasons for the high rates of black morbidity and mortality from diseases and conditions that are preventable, treatable, and curable.

Today a need exists for health care providers, medical researchers, and the health care delivery system overall to acknowledge the horrible history of black medical abuse and neglect, to understand and acknowledge that racism, sexism, and classism exist, and to become culturally sensitive and culturally competent. Furthermore, today, more than ever, a need exists for black people to become more passionate about personal and social transformation, as people focused toward ongoing self-care, self-love, self-esteem, self-empowerment, and emancipation from internalized oppression, depression, passive-aggressive behavior, negativity, anxiety, among

[34] Harriet A. Washington, *Medical Apartheid,* 388.

[35] See 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.

others. Black people must claim the fact that health care is a social good, instead of a private good, that is important for human dignity and human flourishing.

I offer that a theological bioethics from the perspective of the Catholic Church has a major role to play in helping to liberate the ailing captives, moving beyond the long and enduring impasse of the black health care crisis in the United States.

Theological Bioethics on the Black Health Care Crisis

Unlike secular bioethical theories and principles, theological bioethics contains what moral theologian Richard Gula calls 'reason informed by faith.' Theological bioethics includes but also moves beyond strictly reasoned based normative secular bioethical theories and principles to embracing the uplifting and liberating Gospel of Jesus Christ as exemplified in Luke 4: 18-19, "the Spirit of the Lord is upon me, because he has anointed me to bring glad tidings to the poor. He has sent me to proclaim liberty to the captives and recovery of sight to the blind, to let the oppressed go free, and to proclaim a year acceptable to the Lord." It also embraces the message found in Mark 9:14-29. Here the disciples who are desperately trying to heal a boy possessed by a mute spirit. Wherever it seized him, it threw him down. The boy would grind his teeth, foam at the mouth, and become rigid. Jesus appears on the scene and rebukes the unclean spirit, commanding the mute and deaf spirit to come out of the boy. He was cured. In private, his disciples asked Jesus why we were unable to drive out the unclean spirit. Jesus responded, "this kind only comes out through prayer." We, as human beings and human persons created by God are called do the will of God, to pray and to act collectively and ethically as modeled in these liberating messages of the Gospel.

Theological bioethics affirms communal relationships (or as I will later discuss lay health advocates), and includes the principles of Catholic Social Teaching such as human dignity,

global solidarity, the common good, positive rights and responsibilities, participation, and the stewardship of creation in bioethical decision-making. Despite egregious unethical acts done unto black bodies and black lives in clinical medical practice and scientific research, theological bioethics overrides the negative and positively affirms the wholeness and holiness of human life as captured in "the total meaning of black *being* with regard to the past, present, and future."[36] It also speaks to reconciliation and liberation,[37] underscoring the hope for healing and freedom for black people from the memories and experiences of egregious unethical medical acts. For theologian J. Deotis Roberts, this hope exists because "ours 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… Black faith knows what it means to reach out into the darkness and grasp the hand of God, to take one step at a time in the shadows and to find such trust better than light, better than a well-trodden path."[38] This interpretation of hope embodied in reconciliation and liberation serves to counter racist medicine, blacks' perceived racial discrimination, and personal and social ills that perpetuate the highly disproportionate morbidity and mortality rates in black

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[36] Allan Aubrey Boesak, *Farewell to Innocence: A Socio-Ethical Study on Black Theology and Black Power* (Maryknoll, New York, New York: Orbis Press, 1977), 141.

[37] Dwight Hopkins, *Introducing Black Theology of Liberation* (Maryknoll, New York, 1998), 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 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.

[38] J. Deotis Roberts, *A Black Political Theology* (Louisville, Kentucky: John Knox Press, 1974), 64.

communities across the United States. Most importantly, this hope allows us to move beyond what Carmelite Constance Fitzgerald explains as 'impasse and dark night.' For her,

> [i]t is precisely in the [brokenness, and powerlessness of our lives] that one opens the dark mystery of God in loving, peaceful waiting. When the pain of human finitude is appropriated with consciousness and consent and handed over in ones person to the influence of Jesus' spirit in the contemplative process, the new and deeper experience gradually takes over, the new vision slowly breaks through, and the new understanding of mutuality are progressively experienced. [39]

Hence, a situation of no potential is loaded with potential and, for Fitzgerald, the notion of "impasse becomes the place for the reconstitution of the intuitive self." As we, for example, strive toward decreasing and ultimately eliminating the highly disproportionate morbidity and mortality rates from preventable, treatable, and/or curable diseases, Fitzgerald encourages us with these words, "if one yield in the right way, responding with *full* consciousness of one's suffering in the impasse yet daring to believe that new possibilities, beyond immediate vision, can be given."[40] When human beings, who are integrally interconnected to God and neighbor, are fully conscious about the process of impasse and dark night, each one can positively effect personal and social transformation.

All in all, I believe that theological bioethics, which includes faith and reason, encompasses the liberating messages of the Gospel and principles of Catholic Social Teaching to affirm black *being* in the past, present, and future as we move beyond what Fitzgerald explains as the impasse and dark night. One concrete way that I propose to realize these attributes of theological bioethics is through a ministry of accompaniment as depicted in the role of a lay health advocate. From my personal experiences as a Registered Nurse, a theological bioethicist,

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[39] Constance Fitzgerald, *Impasse and Dark Night,* 7.

[40] *Ibid.,* 2.

and a patient, I know that, if one does not understand the way that the U.S. health care system works, including one's health care providers, one should never attempt to negotiate or navigate this system alone; there is power in numbers. We all need advocates. Take someone you trust with you to your appointments.

Ministry of Accompaniment: Lay Health Advocates

In order to better respond to this code black situation in which too many in black communities across the United States find themselves today, I am proposing that parishes, schools, and social agencies develop a ministry of lay health advocates. Ultimately, these advocates are attentive, intelligent, rational, and responsible Christians trained to respond to the black health care crisis, promoting a culture of life instead of a culture of death in their deliberations. Characteristically, lay health advocates must strongly desire to assist in ultimately finding a resolution to the problems and barriers to health care access in tandem with championing primary care prevention and health promotion. The main goal is decreasing and eliminating the highly disproportionate morbidity and mortality rates caused by preventable, treatable, and curable diseases in the black communities. My 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 her/his 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 since of urgency while they respond to a 'code black.' Through an intensive formal formation process they are trained to come to the rescue. Acknowledging the time and dedication needed for this ministry training and formation, their ministries as lay health advocates is to offer an assertive, peaceful, patient, pastoral, and prayerful presence as they accompany the patient/client through her/his 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."[41] The hope is that stronger communal and trusting relationships occur over time, which is important because of the confidential and delicate nature of this ministry.

Ultimately, lay health advocates become very adept at journeying in a mutual and respectful way with the patient/client as they both: navigate the health care system, communicate with health care providers, are not timid about asking questions, negotiate the bureaucratic health insurance companies, follow up with medical concerns or referrals, discuss and organize prescription medications, among many other areas. In addition, lay health advocates are not afraid to suggest and explore further options for health care with their patients/clients, or assist in obtaining second opinions with the patient/client.

Conclusion

In conclusion, I sought to lay out for you some of the philosophical bioethical theories and principles that undergird the black health care crisis in the United States. After the public disclosure of the Tuskegee Syphilis Study, the national commissioners were given the task to formulate principles and guidelines as found in the 1979 *Belmont Report* to address the enduring

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[41] Barbara J. Blodgett, *Lives Entrusted: An Ethic of Trust for Minstry* (Minneapolis, MN: Fortress Press, 2008), 1.

problems of unethical medical and research abuses. Standards and codes have been put into place, but still there are problems of racial discrimination manifested in, for example, blacks' highly disproportionate morbidity and mortality rates from: diseases such as HIV/AIDS, sexually transmitted infections such as syphilis, gonorrhea, Chlamydia, and genital herpes, hypertension, diabetes, various types of cancers, sickle cell anemia, etc; homicides, accidents, lack of childhood immunizations, lack of prenatal or postnatal care, among others. The liberating message of the Gospel captured in the principles of Catholic Social Teaching, and the notions of reconciliation, freedom, and hope characterize a theological bioethics that I argue responds affirmatively to 'code black' to move beyond the impasse and dark night. One concrete way that I proposed to respond to 'code black' is through the ministry of accompaniment as in a ministry of lay health advocates. Essentially, a theological bioethics requires us, indeed demands us to *be aware* as we human beings, created by God, act personally and socially to decrease and ultimately eliminate our highly disproportionate morbidity and mortality rates. We must be aware that the black population is not increasing exponentially. We must take more personal responsibility for responding to the 'code black' situation in which black people find ourselves, nobody else will.

Author and poet Richard W. Smith captures the main argument of this paper in this poem:

Be aware of who you are, others will be and learn. Be aware of what you choose to do, others will notice and learn. Be aware of how others mirror you to you and learn. Be aware of the path you choose, others will notice and follow. Be aware that life will influence beyond what you see. Be aware of the light you shed and the shadow you cast, others will

be. Be aware of the voice you bring—or refuse to bring. Be aware of the story you live—or refuse to live. Be aware. Be aware. Be!

Thank you!