Proceedings of the
2013 Public Health Ethics Intensive
National Center for Bioethics in Research and Health Care at Tuskegee University
April 2-5, 2013
General Information

The Journal of Healthcare, Science and the Humanities is published by the National Center for Bioethics in Research and Health Care at Tuskegee University. The Journal is published in friendship with the Smithsonian Institution Office of Sponsored Projects. The Journal was first published in 2009 by the former Navy Medicine Institute for the Healthcare Humanities and Research Leadership. The Journal was transferred to the new publisher in 2012 as a private publication. The publisher today continues the mission of the Journal to benefit international academic and professional development regarding health, healthcare, the humanities, the sciences, and social justice. ISSN (print): 2159-8800. ISSN (online): 2159-8819.

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Preface

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*Edward Francis Gabriele*

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Preface

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FROM THE EDITOR’S DESK
In this calendar year of 2014, we celebrate one of the truly revolutionary moments in the American Journey, namely the July 2, 1964 signing of the Civil Rights Act. The fiftieth anniversary of this extraordinary moment in the history of social justice in the United States is a time of immense remembering. It is also a time of equally intense preparations for seeing and responding to the social justice needs of the women, men and children of our own day in every land and culture across the globe. This year is a moment in which we remember what has been, in the hope of being “re-membered” and strengthened to meet the challenges of what is before us in time and space. With this anniversary in mind, it well should be asked: How can we realize most effectively the immense meaning of all this?

In our human lives, the most powerful anniversaries we experience are not just static memories. Scholars in culture remind us that the concept of “memory” is itself many-meaninged. Often we recall events that have personal, emotional significance for us. We also often celebrate group events that are important yet do not impact us as much on the personal level. Yet scholars also remind us of a third form of memory. This is a type of dynamically powerful remembering when the past reinterprets the present in the hope of the future. It transcends time and space. It is not as much a cognitive act as a powerful experience that is “entered into” time and time again with greater and greater depth.

As I reflect upon this 50th anniversary of the signing of the Civil Rights Act, I believe we are being invited into that dynamic third sense of remembering that reinterprets and motivates us for that which is to come. This year of remembering calls us to become more deeply aware of the needs of the people of our own times. We are invited to see the social justice needs of our time more clearly, to hear the cries of the poor more distinctly, and to energize our hands and hearts to defend them and raise them up in justice and peace.

This edition of the Journal of Healthcare, Science and the Humanities comprises the Proceedings of the April 2013 Public Health Ethics Intensive sponsored by the National Center for Bioethics in Research and Health Care at Tuskegee University. The theme of the 2013 course was “From A Dream to a Vision: An Ethical Journey.” Much like the third concept of memory mentioned above, course participants “entered into” a living and challenging experience of learning and personal expansion. The pages that follow provide summaries of the course’s keynote addresses, responses, and other related materials. While the materials found on the following pages provide rich academic discussions, they constitute something much more.
Preface

As we see in many popular public domain images from the signing of the Civil Rights Act by President Lyndon Baines Johnson, there was a great sense of enthusiasm among those who attended that marvelous event. Yet the certification of that document was not just the inscription of an approval authority’s written signature to put into effect a particular law. It was far more than that. We might imagine poetically that when the President signed the Act he had rolled up his sleeve and pierced his arm to sign the document with his very life. In a certain respect, like the signing of marriage or ministerial vows, in the person of the President the American People signed with their blood an entry into a new journey of life. This journey commits all of us for the rest of time to the needs of those who have suffered any form of injustice and who cry out to us today and into the future for dignity, equality, and the fullness of life that is ours by the nature of our very humanity.

As you step into the pages to follow, be prepared for a powerfully prophetic journey. Leave aside any baggage that will hinder your pace. You are about to take flight into dreams of justice and peace that long to become waking realities now and into our future.

Lyndon Johnson signing the Civil Rights Act. July 2, 1964
NATIONAL CENTER FOR BIOETHICS
IN RESEARCH AND HEALTH CARE

PUBLIC HEALTH ETHICS
INTENSIVE COURSE
AND
COMMEMORATION
OF THE PRESIDENTIAL APOLOGY FOR UPHSS SYPHILIS STUDY

APRIL 2 – 5, 2013

KELLOGG HOTEL AND CONFERENCE CENTER
TUKEEGERE UNIVERSITY

SCHEDULE AT A GLANCE

TUESDAY – APRIL 2, 2013
8:00 AM – 9:45 AM  Breakfast

MORNING SESSION
WHY WE ARE HERE?
10:00 AM – 11:00 AM  Presenter & Respondents
11:00 AM – 12:30 PM  Group Discussions
12:30 PM-1:30 PM  Lunch

AFTERNOON SESSION
EVOLVING SPHERES OF ETHICS
1:30 PM – 2:30 PM  Presenter & Respondents
2:30 PM– 4:30 PM  Group Discussions

WEDNESDAY – APRIL 3, 2013
7:00 AM– 8:00 AM  Breakfast

MORNING SESSION
LOCAL, NATIONAL AND GLOBAL IMPLICATIONS OF THE USPHS SYPHILIS STUDY
8:00 AM – 9:00 AM  Presenter & Respondents
9:00 AM – 10:30 AM  Group Discussion

ETHICS & DISPARITIES: RACE, GENDER & CULTURE & HEALTH CARE
10:30 AM – 11:30 AM  Presenter & Respondents
11:30 AM – 1:00 PM  Group Discussion
1:00 PM – 2:00 PM  Lunch
Program Agenda

SCHEDULE AT A GLANCE
PUBLIC HEALTH INTENSIVE COURSE

WEDNESDAY – APRIL 3, 2013
AFTERNOON SESSION
ETHICS AND HEALTH: AFFORDABLE CARE ACT
2:00 PM – 3:00 PM Presenters & Respondents
3:00 PM – 4:00 PM Group Discussion

THURSDAY – APRIL 4, 2013
7:00 AM – 8:00 AM Breakfast

MORNING SESSION
ETHICS AND ENVIRONMENTAL JUSTICE
8:00 AM – 9:00 AM Presenter & Respondents
9:00 AM – 10:30 AM Group Discussion

ETHICS AND RESEARCH
10:30 AM – 11:30 AM Presenter & Respondents
11:30 AM – 1:00 PM Group Discussion
1:00 PM – 2:00 PM Lunch

COMMENORATION ACTIVITIES
THURSDAY, APRIL 4, 2013
VIOLENCE PREVENTION
1:00 PM Presenter
6:00 PM Reception (By Invitation Only)

FRIDAY, APRIL 5, 2013
7:30 AM – 8:45 AM Breakfast
GANG VIOLENCE
9:00 AM – 11:30 AM Lecture & Panel Session
COMMENORATION KEYNOTE SPEAKER
12 NOON Luncheon

SCHEDULED SPEAKERS
PUBLIC HEALTH ETHICS INTENSIVE

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The articles in this section are summaries of select keynote addresses.
“Why We Are Here: Because Communal Bad Blood Perpetuates A Legacy of Mistrust”

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Abstract
Within the context of racism, classism and sexism, the intersection of alterity, discriminating language, religion, media, economics, business and unethical practices in public health have presented evidence for people of color and impoverished communities to mistrust the medical care system in the United States. Understanding these issues is critically important for women and men of all cultures and races across the globe. A deeper understanding and appreciation of the in-depth factors surrounding racism in medicine and healthcare, as well as in all cultural activities, is critically important so as to counter the problem of power and its effects on the lives of all persons.

Keywords: medical mistrust, racism, medical apartheid, syphilis study, alterity, Tuskegee, Guatemala

Introduction
“Why Are We Here: Because Communal Bad Blood Perpetuates A Legacy of Mistrust,” posits a hermeneutical lens of suspicion about why persons in the United States, today in the 21st century, are suffering from the repercussions of medical abuse because an unethical bioethics episode occurred for nearly four and half decades in the 20th century in an impoverished predominantly African American community in the rural South. The U.S. Public Health Service Syphilis Study allowed hundreds of men of African descent to participate in a medical research project that caused some of them to lose their eyesight and
live with sores on their bodies. And, as medical members of the U.S. Public Health Service Syphilis Study knew, innocent women were infected with syphilis and passed the bacterial disease that causes blindness and death to their unborn babies inside their wombs. All of the African American (black) men living with syphilis in the Syphilis Study in Tuskegee and Macon County, Alabama eventually died because they were not given penicillin to treat syphilis while penicillin was prescribed for and prevented other American citizens, particularly Euro Americans, from passing syphilis to their wives and children and dying of syphilis.

No Personhood in Medical Apartheid

“I was a nobody and all the men included in the experiment were nobodys, so there wasn’t a lot to say about it for years.”

Ernest Hendon, last survivor of the USPHS Syphilis Study died January 16, 2004

The aforementioned heartrending sentence expresses the human poignancy of the linguistic context of Ernest Hendon’s description of his Sitz im Leibe—one reality setting for life; a man of African descent living in an economically poor rural environment. Although he was not living with syphilis, he was unethically manipulated by medical persons who wanted to research and discover the natural progression of syphilis—a sexually transmitted disease. What is more startling and sorrowful is that the majority of men, in the Syphilis Study, were living with syphilis but they were never told they had syphilis and they were never medically treated. Mr. Hendon and more than 600 other men in the study were emotionally and physically abused and oppressed because they were black and poor. In what is titled, “The Blog of Death,” Mr. Hendon, an adult male in his late nineties, referred to himself and his victimized adult brothers of the United States Public Health Syphilis Study as “Nobodys.”

Semiotics is the study of signs, significance, signifiers, and meaning. The meaning of human skin color and its socially constructed interpretation is one of the subjects of semiotics. The sociological and psychological construct of color symbolism in U.S. society, in this particular case, White-versus-Black—manifests in the intersectoral synergy of the United States medical, public health, media, advocacy, faith and political institutions. Therefore this multidisciplinary intersection influences the moral culture of our communities—local, national and international.

Within the context of semiotics, Ernest Hendon labeled himself and the other men as “Nobodys.” As we critically analyze the meaning of this historically unethical bioethics episode, we must take a close read at the specific language of oppression, which Ernest Hendon used to describe himself as a victim of the unjust syphilis study conducted by the United States Public Health Service.

A “nobody” is a person of no importance, no authority, and a non entity.

Ernest Hendon described himself and the other victims of the syphilis study as a non entity because of the intersection of the misuse of biblical scripture to describe dark skinned people as cursed people, and media gate keepers, including religious communications mediums, consistently using negative stereotyped media images of dark skinned people, to officially symbolize societal pathologies and issues such as poverty, hunger, suffering, violence, criminality, pain and evil.

The Intersection of Religion, Discrimination in Public Health and Negative Media Stereotypes

Religion impacts morality and immorality. Whether an individual practices a religion or not, each person is human and within the context of compassion and respect for humanity, each discipline in the public square should implement an ethos of ethics. However, religious history presents a culture antithetical to a philosophy of moral codes for every member of the human condition.

As one scholar, Ashley Montagu, points out to us from history: “In the year 1455 by papal decree approval was given for the subjugation of infidels by Christians. The net effect of this decree was the official sanction for the enslavement of Blacks, indigenous Americans and other “infidels,” for their benefit of course: the salvation of their souls and their admission into “God’s kingdom.”

One way of capturing what Montagu says is found in the work of Darnell Hunt:

“White = European = civilized = rational = superior = free = good
Versus
Black = African = savage = emotional = inferior = slave = bad”

To continue, sociologist Darnell Hunt offers the aforementioned alterity (otherness of difference) formula to provide an analytical dialogue about how racist societal injustices projected onto and about people of color, poor people, marginalized persons such as prisoners, prostitutes, and the mentally ill impact how unethical public health care practitioners treat the other members of the human condition.

While addressing this communal crisis in the year 2013, it is essential to critically think about how a particular community’s language was used to psychologically make the men, women and youth internalize poor self esteem about their personhood and medically manipulate them to possibly think they were physically inferior because they were of a darker hue; they were black, they were descendents from Africa and their bodies were abnormal. They were black and had bad blood. Bad blood in the black community of Macon County colloquially denoted a person was physically tired or was living with some kind of disease.

During my own investigation about the United States Public Health Service Syphilis Study, I discovered evidence about how privileged members of society took advantage of the colloquial language to manipulate poor black people because they had bad blood. In his work, Bad Blood: The Tuskegee Syphilis Experiment, James H. Jones reported that a white foreman who was working in Macon County, Alabama, literally ordered his black employees to participate in the United States Public Health Service Syphilis Study. The foreman said, “Tell these niggers the health doctor will be at the Possum Hollow School tonight. He’s got some
government medicine to cure the blood disease. A lot of these niggers have got blood trouble, sickly, no count, lazy, but maybe it’s not their fault. This doctor will find out.”

The black men, many of whom were husbands, fathers, grandfathers and outstanding citizens of their communities in Tuskegee and Macon County, Alabama did not know that the United States Public Health Service’s researchers officially labeled the medical study, “Tuskegee Study of Untreated Syphilis in the Negro Male.”

Why were men and women who took the Hippocratic Oath allowed to conduct a medical study not to treat human beings who were living with a life threatening disease which could also be passed on to their wives and children? Evidence also revealed that in 1947, approximately 15 years after the United States Public Health Service’s “Tuskegee Study of Untreated Syphilis in the Negro” was initiated, penicillin became a medicine to treat syphilis but the Negro (black, African American) men in the control and non control group for the medical study were never given penicillin.

Paradoxically, a new version of the Hippocratic Oath was revised in 1943, during the 11th year of the U.S. Public Health Service Syphilis Study. A portion of the Hippocratic Oath read — “I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person’s family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick. I will prevent disease whenever I can, for prevention is preferable to cure.”

According to philosopher Paul Ricoeur, “Symbols give rise to thought.” The United States Public Health Service’s “Tuskegee Study of Untreated Syphilis in the Negro Male” created a legacy of mistrust. This has become a warning symbol for people of color today in the United States, particularly African Americans but not all, not to trust health professions and public health policy makers. The Journal of the National Medical Association revealed the following important point that underscores this.

Over 76 percent of black and 47 percent of white survey participants said they believed that a study similar to the Tuskegee Study could occur again today. Blacks who had heard of the Tuskegee Study were 120 percent more likely than their white counterparts to believe a similar study could occur today.

Based on the results of the above, we can understand deeply the experience of Mr. Ernest Hendon who is cited at the beginning of this article. Mr. Hendon’s 20th century lived experience of medical abuse because he was a black person treated in a scientific study as the other type of human, continues to perpetuate a legacy of mistrust for medical care in the 21st century.

No human being should refer to her or himself as a nobody and be able to use the description nobody to justify why she, he and or an entire community can be inhumanely treated because of the color of their skin and or their socio-economic position.

As Elaine Hegwood Bowen, a reporter for the National Newspaper Publishers Association, confirmed, the bioethics episode of the United States Public Health Syphilis Study involved the lack of respect of persons and the absence of consent guidelines during research. The black men who were approached to become participants in the study were never told they had legal rights to sign an informed human consent form.

The medical and administrative persons who were working on behalf of this unethical study gave the sick, uninformed men free medical exams, free meals and burial insurance in exchange for their human bodies to be used as human medical research guinea pigs. United States Public Health Service Syphilis Study physicians, researchers and other medical personnel let the disease ravage the black men’s bodies and later after the men died, medical personnel performed autopsies to find out how untreated syphilis affected the human body.

What scientific public health method gives a legal right to medical researchers and physicians to determine when a person of color’s body can be determined inhuman while a disease is killing his/her body and yet, perform an autopsy on the dead body of color to help scientists, researchers and health practitioners treat white people who are living with the same life threatening disease?

The Legacy of Mistrust is Global

Ernest Hendon died on January 16, 2004. Six years later, on October 1, 2010, CNN Correspondent Elizabeth Landau reported that Wellesley College medical historian Professor Susan Reverby had discovered that approximately eight years after the U.S. Public Health Service started the “Study of Untreated Syphilis in Negro Males,” in Macon County, Alabama, the American government began another unethical bioethics study in Guatemala. The Guatemala Syphilis experiment focused on how penicillin affected the syphilis ridden bodies of Latino men, women and children who lived in urban settings, while the syphilis experiment in rural Alabama, focused on the natural progression of syphilis in the bodies of black men. Neither physicians, nurses, nor researchers gave the black men penicillin, the medicine that was known to cure syphilis. However, according to Reverby, members of the U.S. medical study team in Guatemala deliberately infected more than 700 Guatemalans with syphilis, oftentimes without their knowledge so that researchers could find out if penicillin really was a cure for syphilis.

The Guatemala Syphilis Study involved nearly 1,000 people who were prisoners in the Guatemala national Penitentiary, soldiers in army barracks, and mentally ill patients and the National Mental Health Hospital. The victims did not give permission to participate in the study.

Womanist Ethicist, Emilie Townes, theorized a construct that described the calculated case of the unethical bioethics episode in Macon County, Alabama. “Ethics took a back seat,” when syphilis was allowed to purposely destroy the bodies of disenfranchised black skinned people and in Guatemala where medical practitioners intentionally infected marginalized brown skinned people with syphilis. The inhuman treatment of bodies of color in general and, in particular, human beings whose skin is not white and who live in poverty stricken urban and rural communities...
created a negative communal bad blood between cultures and classes in and outside the United States.

Health professionals cannot afford to allow ethics to take a backseat in public health care. Trans-discipline scholars, researchers, faith leaders, community advocates, students, medical and public health practitioners need a universal-global-community ethos that will stop creating communal bad blood between races/ethnicities, genders and socio-economic classes and end the perpetual legacy of mistrust that is founded in the evil hegemonic constructs of the intersectionality of racism, classism, poverty, ethnic privilege, homophobia, educational injustice, internalized oppression, environmental injustice, and health care injustice.

In 1972, after the inhumane bioethics episode of the victims of syphilis study was reported by the Associated Press -- the Assistant Secretary for Health and Scientific Affairs appointed an Ad Hoc Advisory Panel to review the United States Public Health Service’s "Tuskegee Study of Untreated Syphilis in the Negro Male." The panel had 9 members from the fields of medicine, religion, law, labor, education, health, administration and public affairs.

The members of the Ad Hoc Advisory Panel met thirty years ago to investigate how the syphilis study was allowed to be conducted and how it impacted the uncommented victims -- and yes, I intentionally use the word victim because the men whose bodies were used for public health research were not told the truth about the experiment, they were not given the opportunity to sign a consent form. Therefore, ethically they were victims-- not willing participants.

The work of the AD HOC Advisory Panel was started in 1972, but in 2013 there is still more work to complete because the tragedy of the Communal Bad Blood experience that was allowed to occur in Macon County, Alabama is still impacting the American and Global Public Health Community. Poor people and people of color, as well as other persons who are socially and politically labeled as the other -- mistrust the public health care community because their ancestors, like the victims of the syphilis study in Tuskegee, Macon County, Alabama and Guatemala were scientifically treated like human guinea pigs.

This then is the reason many interreligious and/or particular communities located in environmentally polluted environments and/or food deserts will not allow members of the science and public health community to approach their congregants or neighbors to ask them to participate in clinical trials or even surveys because there is a legacy of mistrust.

Why is it that oftentimes, members of the medical and public health care community approach me, a faith leader in a predominate faith community of color, to ask congregants or other faith centers of color to participate in clinical trials? Yet, when I ask medical doctors, public health practitioners and/or researchers to provide free health care clinics to serve these same communities they replied, no, or the process for them to offer days of free healthcare to members of faith centers or the community is slow or it never manifests.

Conclusion:

As a womanist public theologian, I suggest it is time for a new paradigm. There must be a respect for all members of humanity approach, with a true heart in full assurance of ethics, with a sincere intent, a true heart to heal and improve the health condition of all people, without any wavering that might be caused by race, gender, class or environmental discrimination or the temptation to create another unethical bioethics episode because of competition for research money or some form of notoriety in the trans-disciplines and throughout the local, national and international community.

Religion impacts morality and immorality. Whether one practices a religion or not, each person is human and ethical decisions effect each discipline. The ethical and unethical treatment of human beings symbolizes the semiotics of an individual's heart and an institution's intentionality for justice or injustice for each member of the human condition.

"The Tuskegee Study of Untreated Syphilis in the Negro Male," epitomizes the inhumanity and evil practiced by the privileged on poor peoples of color, prisoners, prostitutes, poor countries, the mentally ill and youth in poor communities.

This article is based on my invitation as a womanist public theologian, from the National Center for Bioethics in Research and Healthcare at the historic Tuskegee University to lecture at the 2013 Commemorative Anniversary of the 1997 Presidential Apology for the U.S. Public Health Service Syphilis Study at Tuskegee and Public Health Ethics Intensive about the topic, “Why are We Here?”

My response is “We are here because Communal Bad Blood between races, cultures and classes perpetuates a Legacy of Mistrust.”

Death by gunfire is another public health bioethics episode in the 21st Century. Death by gun violence shocked America and the world in the 20th century when Dr. Martin Luther King, Jr, the renowned theologian also known as “the drum major for justice” was violently murdered on April 4, 1968 with a Remington 760 Game Master Chambered Rifle because of the color of his skin. In 2013, days after she performed at the second inauguration of President Barack Obama, 15-year-old Hydiya Pendleton, an honors student at the Martin Luther King College Prep, was tragically shot and murdered by gunfire blocks away from President Obama’s family’s Chicago home. President Obama avowed that more youth have been killed by guns on the streets of Chicago than men and women, at that date, had been killed in war torn Afghanistan. According to law enforcement officials, the majority of the gun violence occurs in urban African American and Latino neighborhoods.

Many youth in Chicago vowed to wear the color orange because they said hunters wear orange so that they will not be shot when they are hunting for wild animals in the woods. Within the context of the semiotic meaning of gun violence against urban African American and Latino youth, youth of color in Chicago are tired of being targets of gun violence because of their social location. Like Ernest Hendon, the last survivor of the U.S. Public Health Service’s “Tuskegee Study of Untreated Syphilis in the Negro Male,” youth in Chicago and across the U.S. are treated like “nobodys.” Guns are not seen as a public health
threat in the United States. Oftentimes more national public policymakers become concerned about gun violence only when shootings occur in predominantly white suburban schools and/or colleges and universities and communities.

When we reflect on the public health repercussions of the syphilis studies in Tuskegee, Macon County, Alabama and Guatemala; the scientific evidence that cancer rates and disparities for Native Americans are higher than for other Americans; and that Native Americans are 500% more likely to die from tuberculosis; we must not forget the tragic death toll of black and brown youth caused by guns. The time has come to begin an intersecting dialogue in the public sphere that transcends negative cultural, academic, business, health and media stereotypes; to intentionally write and implement a proactive public health justice covenant that holds every discipline, including religion, accountable; and to practice an ethical public healthcare justice which benefits every member of humanity. No child, youth, woman, man, impoverished person or community was created to live as victims of “Medical Apartheid.”

“Why are We Here? The Communal Bad Blood of Mistrust is still on Our Hands.”

For Further Reading


From Deep in the Black Belt,
Rescuing Ethical Reason/Reasoning for Ethical Work:
Evolving Spheres of Ethics

A Keynote Address
for the
Public Health Ethics Intensive Course
National Center for Bioethics in Research and Health Care
Tuskegee University, Alabama
April 2013

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Abstract

If contemporary efforts to forge ethical principles for guidance through challenges conditioned by invidious racial implications are to produce results that are intellectually credible and practically effective as fair and just, the taken-for-granted invidious infrastructures of traditions and practices of ethical reasoning must be uncovered and rehabilitated. Hence, the need for a critical appropriation of the history of the involvements of Ethics in constructing and rationalizing a nation-state grounded on White Racial Supremacy in order to rescue and rehabilitate ethical reasoning for the principled guidance required today for the work of realizing justice.

Keywords: African-American, Black Belt, Booker T. Washington, education, ethics, Euro-American, Europe, European, Martin R. Delany, W.E.B. Du Bois, modernity, race, racialist, racism, reason, reasoning, whiteness, white racial supremacy

I. Introduction
The “Whoring” of Reason & Reasoning: Understanding the Issues

It has been said, by one wiser than I’m ever likely to be, that “Reason is a whore who will sleep with anyone”: that is, that characterizing a proposition or the justification of a practice or mode of behavior as reasonable or sanctioned by Reason has been quite promiscuous in human history. It is wise to note historically, in the forging of what is routinely characterized as Modernity (several modernities, even) in Western Europe and the New World of North America, the United States of America in particular, how very much of the whoring of Reason/reasoning was done by men to women, children, other men, othered peoples, othered races, by the men who were the architects, builders, and guardians of racial whiteness made superior and dominating through, and sanctioned by, their invocations of Reason. Racial whiteness as the foundational essence of White peoples was reasoned out and made consonant with Reason/reasoning.

It is wise, as well, to note how the pimps—those responsible for the prostitution of Reason/reasoning—institutionalized their efforts in what I am compelled to regard as whorehouses of learning and education and the pimp-organizations of learned societies, in places of indoctrinating worship and institutions and organizations of theological authority, that sanctified the whiteness that, supposedly, was embodied in and determined the essential, defining raciality of those comprising a particular race as a graceful blessing from their God whose blond-haired, blue-eyed, fair-skinned Son gave up His life in forgiveness of their sins while endorsing their centuries-long, global spreading of programs of genocidal elimination and the enslavement of non-White peoples while raping their lands and women. And, all of this was long deemed ethical by pimps of Reason/reasoning!

It is wise, then, that today those of us taking up the responsibilities of being humanely ethical under the auspices of Tuskegee University’s National Center for Bioethics in Research and Health Care be clear with ourselves and with one another: the various centuries-long programs of White Racial Supremacy were not void of ethical considerations. Rather, the programs were saturated with ethical considerations: with schemes of determinations of good (virtually all that was essentially white) and bad (all that was essentially African-cum-Negro, colored, black, right and wrong, of what constituted being sinful and what would serve redemption; of the just and unjust; the lawful and unlawful. And when the great majority of the European and Euro-American learned, during the long centuries (16th-20th) of enslavement and oppression otherwise of folks African and of African descent, gave studied attention to reasoning about Reason so as to better reason about matters ethical, they apparently felt little ethical compulsion, little felt need, to bring into consideration the genocides and enslavements directed against non-White races as ventures to be concluded on ethical grounds that would serve the well-being of the enslaved and oppressed. By all means, correct me if I am in error by reviewing carefully the histories of studies and articulations of programs of Ethics, of studies of ethical regard for the ventures of genocide and enslavement, by the learned men (mostly) who were the architects and proponents of European and Euro-American Modernity… (For one example, among many, of especially influential canonical histories of philosophy, see Coplestone 2003.)
II. Why the Whoring of Reason and Reasoning?

Why do I characterize the centuries-long rationalizations of programs of inhuman propositions and practices as the *whoring* of Reason/reasoning? Why did the *whoring* emerge and persist? Why retrieve these sordid histories today, on the sacred occasion of commemoration of the lives men and women, of families, that were distorted by ethically sanctioned research experiments the agenda and pursuit of which were structured fundamentally by racism while we rightly celebrate historic milestones made possible by subsequent historic ethical advances such as a Presidential apology for the *profound* ethical breach (though but one of too many) that was that research project, also a 2008 Presidential election and 2012 reelection, and many others advancements, still other bountiful unethical happenings and setbacks not to be ignored?

Why, indeed. In response…

Consider the history of what has been canonized academically as Philosophy in the West. In constructions and mediations of the *history* of Philosophy, there continues the perpetuation of a profoundly influential conflation of *Reason* (considered as a normatively structured and structuring human capacity or complex of functions developed into capabilities through proper nurturing and exercise of the capacity or complex of functions) with *reasoning* (that is, the exercise of the capacity or function-complex). And the institutionalization of this conflation has been legitimated by the valorizing of particular modes of right Reason/reasoning as the arbiter and provider of *truth, good, justice*, etc., as a consequence of the *proper* exercise of the capacity/capabilities. Of course, what has been and continues to be deemed as *proper* varies according to the reasons/reasonings judged as such by particular canonical philosophers honored as the guardians of Reason and proper reasoning, and honored as the acclaimed architects or excavators of the principles and practices of right Reason and reasoning.

However, throughout the constructions and institutionalizations of the canonizations, the capacity and capabilities for right reasoning were assigned to specific men, and during the seventeenth and eighteenth centuries were assigned to men identified as being of a *specific* race identified by the racial codes of white and of Europe (*European*) that served as the physiognomic and geographic groundings, and the subsequent symbolic vehicles, for the presumed ontological (even metaphysical) essence of *whiteness*. Thus, the practices of institutionalizations and mediations of canons and canonical practices, continuing to this phase of history, involved instantiations of historically and culturally (thus politically) specific programs for the specification and cultivation of the capacity/capabilities, and the sanctioning of rules, for right Reason/reasoning, practices that were enabled by and enabled particular philosophies of history declaring as being fulfilled in the unfolding of imperialist civilizational projects enforced globally as *discoveries* of *New Worlds*.

Initially, there were hardly any denials of the racial priority declared as having been bestowed on the thought-leaders, philosophers and theologians among them, by their God who favored the white race with the superiorities by which to fulfill His plan for planet earth. Subsequently, these claims were rendered internally self-destructive (contradictory) by efforts to soften the racialism and racism by the protective conceit of recasting the characterization of the supposed normative rules governing the nature and exercise of Reason/reasoning as historically, culturally, and anthropologically *neutral* because characteristic of Man as such, efforts that were intended to rationalize and sustain the very projects of racialized imperialism and genocide that were vehicles for the particularized racist distributions of the pluses and minuses of the historic globally expansive instantiations of the social, political, and cultural economies of White Racial Supremacy. It is the whole of these distorting corruptions of human reason/reasoning in service to invidiously gendered racialism that I characterize as *whoring*. And, there came to be much *sleeping around* by this whoring of Reason/reasoning, the justifying and legitimating of the rationalizations of invidious discriminations in service to exploitations, across the long centuries of racialized holocausts of genocide and enslavement through which was forged the United States of America. (For evidence of the significant investments in racializations, and in racism, in the thought of philosophers who have been canonized as fabricators of ethical and other understandings and aspirations constitutive of the historically axial forms of *Modernity*, see some of the signal articulations by these philosophers anthologized in Eze 1997 and in Bernasconi and Lott 2000.)

Why? To construct and rationalize particular unifying valorizations of shared life, by and for White folks, among whom many of the reasoning/rationalizing leaders-of-thought and praxis were convinced of the favored place of their race in the Great Chain of Being: just beneath the angels, with the *Trinity* of Holy Ghost, Christ, and God at the top, and given dominion over all of the earth, including birds in the air, fish in the sea, and beings beneath the earth. (For a critical intellectual history of notions of a chain of being, see Lovejoy 1936.) Regulating this favored, shared, racially segregated life, underwritten by genocide and enslavement directed against non-white races, required both principles and practices of ethical guidance and sanction. Consequently, such principles and practices were congealed into customs and traditions and, over time, were institutionalized, continuously justified and valorized through refining rationalizations, then propagated as schemes of ethical principles for regulating actions and behavior.

We would do well, then, to keep in mind always the mutually reinforcing reciprocal relations involving ethics and social life. As noted by Hegel, the racist canonical philosopher of great significance: “The owl of Minerva spreads its wings only with the falling of the dusk” (Hegel 1821/1967, 13). That is, “philosophical clarification of life is produced after the fulfillment of historical development, after—not prior to—experiences. Reasoning out to philosophical clarity and assurance the rightness of Reason/reasoning, of the ethical rightness of living, comes after, and as a corrective to, failed or successful efforts of life-making and living. The racialized life-making efforts of acquisitive, globalizing expansions of European peoples into Old World and New World locales they sought to unify through the fabrication of an essentialized racialization of the substance and ethic of a unitary *Whiteness* that would “make one of many” of European peoples by reducing to racial oneness the heterogeneities of cultural and other *national* differences. The putative unity of a shared racial singularity was the hoped-for resolution of the challenges of anthropological and historical diversity and the avoidance of destructive fratricidal *intra*ncial competitions. Here, then, a paradigmatic example of life-making made ethical: regulating intergroup relations by principles taken as appropriate for securing the well-being of a favored *race*, and putative favored civilization, as a consequence of conflictual encounters with invidiously racialized others.

Why rehearse this history? In order to clarify my position as a professional academic philosopher honored by being called on to address a sacred annual venture in ethical
reasoning (the Public Health Ethics Intensive Course and the sponsoring National Center for Bioethics in Research and Health Care): that I come not with learned guidance from the discipline of academic Philosophy—though I hold out hope that worthwhile learning and learnedness without whoring is to be had from some efforts within the discipline—but am morally compelled by understandings I draw from Black living across the centuries of engagements with racialized and racism-engendering livings of White folks, and with others not White, to forswear the discipline as an authoritative, ready-to-hand resource of ethical guidance. In order to make clear that I offer my considerations as possible contributions to those who brought into being and sustain this sacred occasion and Center devoted to ethical work: namely, that on behalf of ethical life to be forged, lived, and enjoyed by Black folks, to the good of folks White and otherwise, reasoning about ethical matters must be rescued from the pimps and revised so as to be put to sustained service reclaiming, rehabilitating, protecting, nurturing, and advancing the very humanity of folks African and of African descent, Black folks.

However, let us not become, be, or remain guilty of the very serious dehumanizing ethical breach of forgetting, or of not recognizing, that the rescue and caring for reasoning on behalf of ethical guidance for caring for and advancing our own humanity will free up White folks suffering the sickness of racism for the rescue and rehabilitation of their humanity. For the evidence of more than three centuries of racism made sacred by ethical principles from whoring reasoning makes abundantly clear that we Black folks, and we White folks free of the active virus of racism, and other folks devoted to ethical principles and practices promoting cosmopolitan humanisms, cannot, cannot, leave the rescue and rehabilitation of ethical reasoning to White folks alone. It would not be in the best interests of White folks, even (best being beyond the whoring of reasoning in service to White Racial Supremacy). It definitely would not be in the best interests of the lives and well-being of those who have and do suffer from racism to be so irresponsibly forgetful, or to fail so significantly, to have proper concern for the rehabilitation of White co-humans suffering from racism. For all of these reasons, then, it is necessary to bring back the past for critical review in order to become more fully knowledgeable about what's needed, what resources are at hand and/or need to be acquired, in order to have personal and shared lives conditioned by ethical principles and practices appropriate for and conducive to flourishing without racism. If we don't know where we're coming from, then any road will take us wherever we know not that we are going…

III. From Whence: Life in the Black Belt

Let us take a brief look back at the forging of Black life in these United States centuries ago (1600s). For millions of Africans who survived capture and being sold into enslavement; who survived the Middle Passage too horrible to indulge in trying (and failing) to imagine fully; who survived the Breaking Grounds; who survived all of the ruptures of sociality and development through which persons become human were remade as less-than-human chattel slaves and still bequeathed successive generations that include those of us living today—for very large numbers of these foremothers and forefathers the primary sites of relocation in North America were in portions of particular colonies, later states, in an area within the agricultural South—southwest Tennessee to east-central Mississippi, east through Alabama to Georgia—that became known as “the Black Belt.” However, it is important to note that the characterization of the blackness of the region was also a reference to the dark, rich soil that was a significant feature of its topology, which is why the region became the geopolitical foundation of the agricultural political-economy that was based on the cross-generational enslaved labor of continuous shiploads and breeding of captive individuals from African peoples and their surviving descendants. Millions of these peoples, forged into a putative unified, singular race by the forced and enforced practices of invidious racialization across centuries of successive generations, would continue to reside in the region through the mid-nineteenth century when, after formal Emancipation (1893) and the end of the Civil War (1860-1865), millions would migrate west (to Texas, Oklahoma, California), north (to St. Louis, Missouri; Cincinnati, Dayton, and Akron, Ohio; Chicago, Illinois; Detroit, Michigan; Milwaukee, Wisconsin), and east (from Virginia and Maryland to Washington, DC; to Pennsylvania, New York City (Harlem), Connecticut, and beyond…) to join generations of free and freed Black folks many of whom were residents for several generations. Until these migrations (in some cases even after), numerous counties in the region contained more Black people than White people. Hence, in this double sense, “the Black Belt…” Capture, transport, seasoning, and distribution, through sales, to plantations and other institutions and enterprises, all rationalized and rendered ethical through the exercises of whoring Reason/reasoning in service to episteme (schemes of authoritative knowledge) of White Racial supremacy and of negro racial inferiority, were, in total, the forge in which the cross-generational millions of Black folks were compelled to refashion on the fly psychological, social, and cultural strategies and practices by which to survive and endure new languages and modes of communication; new senses of history and temporality (senses of pasts, the present, and of questionable future possibilities and prospects); new genealogical and cultural lineages, thus new intra- and inter-group relations; new practices of work and play; new strategies for forging and sustaining psychological resilience, for rendering life sacred the circumstances notwithstanding — really, because of the circumstances. Black folks in the Black Belt, and elsewhere, had to become a people in order to endure, not just survive, as they worked the land, first and foremost…

We who have followed the plow…have developed a secret life and language of our own. When we were first brought here from our innumerable African tribes, each of us spoke the language of his tribe. But the Lords of the Land decreed that we must be distributed upon the plantations so that no two of us who spoke a common tongue would be thrown together, lest we plot rebellion. So they shackled one slave to another slave of an alien tribe. Our eyes would look wistfully into the face of a fellow-victim of slavery, but we could say no word to him. Though we could hear, we were deaf; though we could speak, we were dumb!

We stole words from the grudging lips of the Lords of the Land, who did not want us to know too many of them or their meaning. And we charged this meager horde of stolen sounds with all the emotions and longings we had; we proceeded to build our language in inflections of voice, through tonal variety, by hurried speech, in honeyed draws, by rolling our eyes, by flourishing our hands, by assigning to common,
simple words new meanings, meanings which enabled us to speak of revolt in the actual presence of the Lords of the Land without their being aware! Our secret language extended our understanding of what slavery meant and gave us the freedom to speak to our brothers in captivity; we polished our new words, caressed them, gave them new shape and color; a new order and tempo, until, though they were the words of the Lords of the Land, they became our words, our language. (Wright and Rosskam 1941: 40)

We did more, we Black folks. In the circumstances we deployed our new language with compelled thoughtfulness. We were, indeed, compelled to think! Compelled to endeavor to make sense of our circumstances: where we were in contrast to where we used to be; who we were told we were in contrast to who, initially, we understood ourselves to be in terms of our natal languages and identities in natal lands; then in contrast to the invidious, soul-distorting characterizations of our being and persons, of our family formations and modes of sociality, of our peoplehood formed and sustained for centuries before the holocaust began and that being forged in the furnaces of enslavement. Our very humanity and integrity were denied through whoring metaphysical reasonings and rationalizations that redefined and revalued our ontological position on the Chain of Being by way of a categorization designated for living beings with rational capabilities sufficient only for obedient lifetimes of dominated, uncompensated labor, service, breeding, and merrymaking for the benefit of the Superior Race.

Against this we were compelled to reason in conjuring new personal and shared identities that gave us vital protection against the social death required by the ethics and politics of enslavement. (For a discussion of slavery and “social death,” see Patterson 1985.) We were compelled by the circumstances to choose continued living or death, whether by our own hands or by the hands of others. And in choosing continued living, we were compelled to conjure out ethical principles and practices by which to structure and guide living, then and across the futures hoped for, principles and practices that would be calibrated by our notions of good and bad, right and wrong, justice and no justice, and, especially, notions of freedom. We didn’t need, had neither the time nor circumstances for, the leisureed considerations characteristic of well-off philosophers devoting their productive time to thinking about the epistemological requirements to be met to validate and thereby give authority to the ethical notions and practices by which we would survive the ordeals of enslavement, by which we would endure and set up successive generations for securing and enjoying freedom with justice. No, the validation had to be determined in the course of our enduring the conditions of living by which, subsequently—“by and by…”—we would win conditions within which to forge and enjoy forms and qualities of living in which we would be fully recognized and respected as human beings of integrity as Black folks. For engaging in such thoughtfulness we were compelled to rescue Reason/reasoning from the pimps and whorehouses of the ethics of White Racial Supremacy.

We did still more. Out of creative adaptations of forms of imposed and retained religions and theologies we forged new forms and dimensionalities of spirituality. The difference? To my mind the clarifying distinction has best been captured in the observation of those who have noted that “…religion is for folks who are afraid of going to hell; spirituality is for folks who have already been there…” that is, who have lived it. There the crucial difference: living in and enduring hell. There the motivating source of our spirituals and

blues, the sacred and secular musics created by a people enduring hell; musics through the creation, expression, and relieving consumption of which Black folks were able to cultivate and sustain hope through faith, nurtured, among other places (juke joints, in work-fields…) in church-gatherings of various kinds led by women and men preachers and singing-leaders fired-up by the Spirit(s):…

…the preacher’s voice is sweet to us, caressing and lashing, conveying to us a heightening of consciousness that the Lords of the Land would rather keep from us, filling us with a sense of hope that is treasonable to the rule of Queen Cotton. As the sermon progresses, the preacher’s voice increases in emotional intensity, and we, in tune and sympathy with his sweeping story, sway in our seats until we have lost all notion of time and have begun to float on a tide of passion. The preacher begins to punctuate his words with sharp rhythms, and we are lifted far beyond the boundaries of our daily lives, upward and outward, until, drunk with our enchanted vision, our senses lifted to the burning skies, we do not know who we are, what we are, or where we are…

We go home pleasantly tired and sleep easily, for we know that we hold somewhere within our hearts a possibility of inexhaustible happiness; we know that if we could but get our feet planted firmly upon this earth, we could laugh and live and build. We take this feeling with us each day and it drains the gall out of our years, sucks the sting from the rush of time, purges the pain from our memory of the past, and banishes the fear of loneliness and death. When the soil grows poorer, we cling to this feeling: when clanking tractors uproot and hurl us from the land, we cling to it; when our eyes behold a black body swinging from a tree in the wind, we cling to it… (Wright and Rosskam 1941: 73)

Yes, even as we reclaimed for burial what remained of the strange fruit hung in trees and controlled us—the ubiquity of the terrorism, it was withdrawals from this reservoir of Spiritualities that steeled us against the justice meted out by the lynch mobs. Conducted and witnessed by good White folks, Christian and otherwise, more than a few came to participate in the creation and enjoyment of the spectacle—some even bringing their children to witness, as well, along with their carefully prepared picnic eats—so that through participatory witnessing the totemic ritual of inflicting death on Black folks would purify and sanctify racial Whiteness while confirming, through ritual practice, that the ethical way of life of White Racial Supremacy would be protected by any means necessary. (We should consider: Today our nation-state wages war on terrorism. Yesterday a great many White folks in our nation-state waged ethically sanctioned terroristic war on Black folks….)

Still, we Black folks endured. In part by finding, creating, and expressing beauty and joy in the midst of terrorism, ugliness, pain, and sadness; by laughing at comedy in the midst of tragedy; by immersing our souls in the soothing, relieving blueness of song and dance in the midst of darkness—all with artfulness distinctive of a folk culture forged out of the old and newly acquired/adapted/created cultural resources of involuntarily relocated Africans and their descendants.
And we saw to our chillun as bes’ we could, too. Lovin’ dem, passin’ on to dem the hope we forged the strength to sustain. Through the making and nurturing of our chillun, we forged a cross-generational people sustained by traditions of a folk culture of values and practices that sought the guidance of right and justice to be had in freedom, notions the meanings and guidance of which did not come from the whoring Reason/reasoning of the White folks fostering White Racial Supremacy. The clear evidence of the ethical significance of the difference in meanings? In our becoming a people by our creative adaptations to the enforcements of racialized enslavement and terrorism, we did not require of ourselves expiation of guilt and rage via the dehumanization, nor the genocidal death, of White folks. Not vengeance, but pity and understanding of White folks we cultivated. Wanting not the denial of all to White folks in retribution for all that had been denied us, we wanted, rather, our fair share in keeping with our contributions of labor to the production of what was created that could be enjoyed by all who earned, merited, or needed a fair share.

IV. HBCUs: Centers for the Rescue of Reason/reasoning?

But, Black folks took on the responsibilities of preparing themselves to make productive contributions by gradually, but determinedly, formalizing our learnings and the mediations of them. For our chillun as well as for our adult selves, we were compelled by the circumstances of dehumanizing enslavement to gain knowledge of various kinds through enduring living, to gain knowledge pragmatically, you might say (though with no need to seek certification from the custodian of the tradition of Pragmatism canonized in some departments of Philosophy), as called for explicitly, way back in 1852, by the philosophically-minded engaged Black thinker-activist Martin R. Delany. (See Delany 1852 (2004).) Moreover, to have endurance continue across subsequent generations, it was socially necessary to congeal the experience-grounded knowledges into communicable and understandable formulations, appropriate for distribution to folks in various roles and appropriate for varying kinds of circumstances, and to cultivate tested and proven strategies by which the experience-verified knowledges could be passed on successfully to successive generations who, in taking them up as structuring intellectual and pragmatic guides to living, would enjoy better lives, ethically as well as materially.

The generations, then, had to be taught, had to be educated. But by folks, initially, who were themselves denied formal education; folks of whom it was determined, scientifically, that they were, by racial nature, incapable of being formally educated, which efforts, in any case, would be both unethical and impractical since it would only make us bad slaves! Still, we were compelled to forge ways of distilling experiences into pragmatically verified knowledges, and to forge ways of institutionalizing the production of such knowledges and of mediating them to successive generations. We developed schooling before we were allowed to have schools. And the segregated schools that, centuries in coming, were allowed us were constructed and resourced to comply fully with the scientifically settled, theologically sanctioned, and ethically valorized determinations of our racialized inferiority.

All the more reason that we were compelled to make of these educative ventures more than was intended, expected, or allowed. As with the forging of our language, we forged and/or adapted programs of learning and teaching appropriate for our schooling given our circumstances. And, within and beyond the Black Belt, we undertook to found, support, and operate our own schools, in keeping with our pragmatically determined agendas and philosophies of education, our philosophies of history, even when we had to do so surreptitiously while operating in plain sight, seemingly conducting our lives in keeping with the agendas of the Leaders of the Superior Race. After Emancipation (by Presidential order in 1863, the order made effective in 1865), and in the Black Belt especially, provisioning for the nurturing and refined development of the souls of Black folks, spiritually and educationally, so as to enable us to meet the formidable challenges of freedom in a nation-state undergoing profound transformations (reconstruction after the devastating 1860-1865 civil war that is estimated to have taken more than 750,000 lives but brought about the implementation of U.S. President Abraham Lincoln’s Emancipation Proclamation; the ascendancy of industrial and finance capitalisms centered in urban locales of the North and East over the slave-based agricultural capitalism concentrated in the South and its Black Belt) would be accomplished to significant extents by means of, and with the assistance otherwise, of Black churches forged into denominations with social as well as theological agendas, accomplishments aided, as well, by other organizations of Black folks—and by White folks who had recovered from, or had the good fortune never to have succumbed completely to, the soul-distorting sicknesses of the philosophies and theologies of White Racial Supremacy. We were compelled not to entrust the schooling of our successive generations to the ethical guidance of the sick White folks, in the Black Belt especially…:

Deep down we distrust the schools that the Lords of the Land build for us and we do not really feel that they are ours. In many states they edit the textbooks that our children study, for the most part deleting all references to government, voting, citizenship, and civil rights. Many of them say that French, Latin, and Spanish are languages not for us, and they become angry when they think that we desire to learn more than they want us to. They say that “all the geography that a nigger needs to know is how to get from his shack to the plow.” They restrict our education easily, inasmuch as their laws decree that there must be schools for our black children and schools for the white, churches for our black folk and churches for the white, and in public places their signs read: FOR COLORED and FOR WHITE. They have arranged the order of life in the South so that a different set of ideals is inculcated in the opposing black and white groups. (Wright and Rosskam 1941: 64)

Tuskegee Institute was but one of several institutions founded for the educational lifting-up of Black folks—from the uncompensated work-life of enslavement and the folk culture that enabled and sustained endurance of enslavement and the peonage being fostered on Black folks during Reconstruction—to modes of life of higher civilization exemplified in the living of the best of the White race and by a talented ten percentage of Black folks (see Du Bois 1906). Rejecting the whored reasonings of White Racial Supremacy, Booker Taliaferro Washington was emblematic among the founders of these new institutions. He sought not to disprove the reasonings through arguments, but, first and foremost, by the living evidence of productive performance: that is, by producing Black folks educated to the acquisition and exercise of particular skills and competencies, and with particular casts of refined character. In turn, these Black folks were to establish their productive independence through educated work (disciplined, acquisitive, profitable work while serving markets of folks White and Black) while comporting themselves in accord with certain of the norms of industrial civilization, norms that Booker T. and other Negro leaders were convinced were not achieved
and lived as a condition of racial particularity, thus were not the exclusive accomplishment of White folks. (However, for some of these leaders and educators, for Booker T. in particular, the quest for full political rights and, especially, for social equality, were to be foregone initially—at least publically).

The missions and missionary work of Tuskegee Institute and the other institutions we now refer to routinely as the Historically Black Colleges and Universities (HBCUs), many of them situated in the South, some, Tuskegee among them, situated in the very heart of the Black Belt. Having made a deliberate founding decision, as a graduate of Hampton Normal and Agricultural Institute, to follow the directive of General Samuel Armstrong, founding principal of Hampton Institute, to establish a Hampton-like school for Negroes in Alabama, Booker T. Washington took up the work of “lifting the veil of ignorance” from educable Negro peasants in Alabama but a decade-and-a-half out of enslavement (1881). These were people targeted for the crushing near re-enslavement of tenant farming and sharecropping, with advancement in life otherwise brutally curtailed by terroristic violence. Still, Washington persisted in his chosen work, convinced that Negroes could and must learn how to “do for self”; must establish economic independence as a complement to social rehabilitation and development, and as a condition for eventual political equality. And this learning, of the kind that Tuskegee Institute believed, was historically and socially necessary to counter fully and to displace completely the crippling, forced learning inculcated during the long centuries in the schooling of enslavement, most especially that of having learned to devalue the uncompensated modes of work forced on Black folks and identified, through assignment to them, as “nigger work” with which no self-respecting (White) person of any means should be associated even though the work was socially necessary in the context of the political economy of capitalist production. Hate the forcing, not the work, we might paraphrase a focal teaching of Booker T.’s philosophy of education. Put differently: Value socially necessary work!

But this valuing would require a strenuous revaluing, not only of various forms of work, but of the very nature and being of the worker: that is, a revaluing—a profoundly ethical/revaluing—that would make of niggers respectable, self-respecting Negro women and men of educated competence and accomplishment fashioning and sustaining homes, families, institutions, organizations, and communities in step with accomplishments in agriculture, science, industry, social life, and the high arts characteristic of the best Western civilizational developments of the late nineteenth and rising twentieth centuries. Yet, for this historically crucial revaluation to even be possible, and to be followed by learning fostered by institutionalized normal school (then by education of college and university-caliber) formal education, the very idea of Negroes as living beings had to be rescued from the pimps and whorehouses with whom and wherein ethical considerations had been enthralled for nearly three centuries. Tuskegee Institute was founded for this sacred rescue work, and has been sustained, now as Tuskegee University, in the pursuit of an evolving mission. Today that mission includes having taken on, through the National Center for Bioethics in Research and Health Care, the crucial, historic work of rethinking thoughtfully and ethically matters ethical while being guided by, and responsible to, the need for the ethical rehabilitation of ethical thinking and practice required by the centuries-long history of the forced presence and dehumanizing enslavement and oppression of African peoples and their descendants in the Americas, among other sins, perpetrated by the whoring of Reason and reasoning in service to White Racial Supremacy.

References
Local, National and Global Implications of the USPHS Syphilis Study for Women

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Abstract

The United States Public Health Service (USPHS) Syphilis Study, carried out in Tuskegee is a critical part of world history. Although it took place in one geographic location—Tuskegee, Alabama (and later in Guatemala), it has implications across the world. What are these implications not just for the U.S. but beyond? Specifically, how does this study influence the way we navigate our work among vulnerable populations, like women and children? Why is the information and knowledge about this study, so limited worldwide? What framework can be used to understand and engage with core lessons within our complex world? Reflection on these questions allows us to tease out selected lessons learned from the Syphilis study. The lessons must be the pillar in which we build a world that promotes the growth and flourishing of ALL human beings, regardless of socio-economic status, race, ethnicity, gender or religion.

Keywords: USPHS, women, global

Introduction

The USPHS Tuskegee Syphilis Study can inform us in many ways. Based on my fields of study—international development, communication and public health policy, and my personal experiences, I would argue that, today, the Tuskegee study could be explained and understood globally within the lens of three key broad areas—educational field of study or approach to learning (especially as they pertain to research and evaluation), globalization, and communication (especially media). Ironically, they are all closely linked and build on one another.

With my limited knowledge on the key lessons from the Tuskegee study, coupled with and guided by my fields of research and practice, this paper will seek to ask and engage with the questions: What are people’s vulnerabilities? What factors facilitate and perpetuate those vulnerabilities? How do we shift our paradigm to reducing people’s vulnerabilities by increasing their capabilities? The examination of these questions, using the three broad areas—fields of study, globalization and communication—can begin to provide insights into how the Tuskegee study links people at various levels—local, national and global—especially as this process pertains to women.

Linking Local, National and Global

Educational Context: Field of Study

The way we see the world, or our worldview, is influenced by many factors. These could include: family, culture, beliefs & values, and educational experiences, among others. Similarly, in academia, the way in which an issue is framed, often determines the response. Bryant Myers, in his book, Walking with the Poor, argues that, “the way we understand the nature of poverty and what causes poverty is very important, because it tends to determine how we respond to poverty” (Myers B., 2011, p. 14). This analogy goes beyond the framing of the issue; it affects the way we measure the outcome and impact.

The Tuskegee study has traditionally been explained within a Biomedical and Bioethics model or framework. That has been extremely helpful especially in understanding the morality and ethics around the process. However, the conversation must not end there. A broader look at the study, within an international development perspective, would help in framing the conversation for increased impact and response. Because the international development field encompasses so many sectors—education, health, agriculture, public policy, among others, it also has much to contribute to the dialogue. There are many forces challenging the traditional, modernization (Westernization) paradigm of development, which generally equates human progress with economic growth (Kingsbury, Remenyi, McKay, & Hunt, 2004). There is a growing consensus that development must be about placing the individual or community, rather than external interests, at the center of any process seeking to impact people’s lives. This human centered development approach has been defined as:

……a means of enlarging people’s capabilities in terms of skills, productivity and inventiveness. This necessarily implies an empowerment that allows them to participate actively in their own development. Development in these terms is something that is done by people rather than for or to them. And it is this essential of people’s participation which defines the right to development in both its economic and political aspects (Reoeh, 1994, p. 125).

In relation to the international development field, global health has increasingly been viewed from the lens of any issue that concerns many countries or is affected by determinants that are transnational. The ‘global’ often refers to the scope of the problem and not so much limited by location (Kaplan J. et al., 2009). The use of the term global health instead of international health highlights a growing preference and draws attention to a parallel shift in philosophical understanding and attitude in engaging with complex global issues. This emphasizes “the mutuality of real partnership, a pooling of experience and knowledge, and a two way flow between developed and developing countries. Thus, global health uses the resources, knowledge, and experiences of diverse societies to address health...
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challenges throughout the world.” (Kaplan J., et al., 2009, pp. 1994-1995). The authors go on to emphasize the interconnected nature of global health and define it as:

…an area for study, research, and practice that places a priority on improving health and equity in health for all people worldwide. Global health emphasizes transnational health issues, determinants, and solutions; involves many disciplines within and beyond the health sciences and promotes interdisciplinary collaboration; and is a synthesis of population-based prevention with individual-level clinical care (Kaplan J., et al., 2009, p. 1995).

With the increased use of clinical trials, around the world, understanding the Tuskegee study within a global health lens would clearly be beneficial to more populations, especially those who are extremely vulnerable, like women and children.

Recognizing that “increasingly the nature of the health problems rich and poor countries have to solve are converging”, the World Health Organization (WHO) put together a Commission, made up of researchers, policymakers, and civil society, to document the evidence of promoting health equity and to facilitate and foster a movement that can achieve this global mission (WHO, 2008). So what are these social determinants that have helped create a more holistic view of health? The Commission outlines:

The poor health of the poor, the social gradient in health within countries, and the marked health inequities between countries are caused by the unequal distribution of power, income, goods, and services, globally and nationally, the consequent unfairness in the immediate, visible circumstances of people's lives—their access to health care, schools, and education, their conditions of work and leisure, their homes, communities, towns, or cities—and their chances of leading a flourishing life (WHO, 2008, p. 1).

WHO continues on to argue that this inequity in health is not a natural phenomenon but is frequently the result of poor social policies and programs, unfair economic conditions undergirded by bad politics (WHO, 2008). An example of this inequity, within the social determinants framework, is the healthcare worker shortage. It is estimated that 1.3% of the world's health workers care for individuals who experience an estimated 25% of the burden of disease. The authors continue to make the case that, “there are 57 countries with a critical shortage of healthcare workers, a deficit of 2.4 million doctors and nurses and midwives” (Naicker, Plange-Rhule, Tutt, & Eastwood, 2009, p. 60). This is leading to collapsed healthcare systems, especially in vulnerable communities and doctors and nurses and midwives” (Naicker, Plange-Rhule, Tutt, & Eastwood, 2009, p. 60).

However, the approach of social determinants of health has its own critics. Jennifer Ruger, Professor at Yale University, highlights the debate on how to measure social determinants, outside of the health care system, especially when there are policy implications (Ruger, 2004). This has to continue to be a challenge that practitioners address.

Communication

Communication played a key role in the Tuskegee Syphilis study. There was definitely a culture of silence in this process which meant that communication only happened within a limited and defined circle of researchers, government officials and practitioners. It was the media that finally broke the story about the study.

Communication often assumes there is some transfer of information or knowledge. Traditional development theories, like modernization or diffusion of innovation, often assume communication has to be one way, from the sender, who often controls the message, to the receiver, who is the decoding vessel. It is based on the trickle-down theory with the assumption that people's culture and knowledge or information deficit undermine development and become the bottlenecks of progress (Mody, 2003). This paradigm allows those in control of the process to ignore or marginalize those with less power, if any at all. However, how this information is shared, transferred or used determines the effectiveness and earnestness of the process. Most communication specialists would argue that feedback within a dialogical process is central to effective communication.

In certain situations, it can be the lack of information or access to wrong or dishonest information that can be harmful. In follow-up studies, researchers sought to understand participation in biomedical research especially based on the level of awareness of the Tuskegee Syphilis Study and the presidential apology (Katz, et al., 2008). This demonstrates there was some level of awareness using modes of communication to inform people about the study. The fact that the understanding and knowledge of the Tuskegee Syphilis study is often sketchy, with limited information, raises the question of communication effectiveness or the driving purpose.

For communication to make an impact in a society, it must support the full development of people. Non-disruptive and sustainable change must come through a society's communication system (Lundstrom, Smith, Kenyi, & Frerichs, 1990). This idea is supported by Paulo Freire, a community activist and educator, who suggests that a dialogical model of communication and education must encourage the mobilization of local resources and support critical thinking that ensures solutions come from that particular context (Kiiti, 2007). Freire argues that every human being, no matter how ignorant or submerged in the culture of silence is capable of looking critically at his/her world in a dialogical encounter with others (Freire, 1984). Shirley White's ideas complement this approach. She terms it as 'participatory development communication' which is “a two-way, dynamic interaction, which through dialogue transforms 'grass-roots' people and enables them to become fully engaged in the process of development and leading to self-reliance (White, 1999, p. 36).
Globalization

As if defining globalization wasn't difficult enough, a consensus on whether the process is increasing economic growth or reducing inequality and poverty, in a sustainable way, is even more elusive. This process of global free-market economy has raised questions, especially by countries of the Global South, surrounding: tangible benefits following their allowing access to their economies, unfair trade rules, growing inequalities of wealth and opportunities, environmental degradation, social and cultural problems, among others. (Khor, 2004)

Thomas-Slayer has explained it well in her book, *Southern Exposure*. She argues that "the global economy is rearranging, linking, and even uniting us in new ways. The key is the marketplace—global capitalism—and the ways in which the technology of the information age has transformed it" (Thomas-Slattery, 2003, p. 146). Other development practitioners have suggested that, although globalization is often defined from an economic perspective because of its direct impact on people's lives, other interpretations of globalism include, "a more generalized interdependence, the collapse of time/space, communications, culture, political institutions, global institutions, and levels of global intervention (Kingsbury, Remenyi, McKay, & Hunt, 2004, p. 94). These definitions and ideas are another reminder, that communication is a core aspect of the globalization process.

Some researchers and health practitioners have explored the link between clinical trials and globalization especially since many pharmaceutical and device companies have adapted this as their business model (Glickman, et al., 2009). Glickman and his colleagues continue on to highlight the benefits of clinical trials such as building results accurate and valid, and can they be extrapolated to other settings?

What is the potential for exploitation of research subjects? Are the trial specialists tend to understand their jurisdiction and local context much more easily than foreign conditions or practices that might be introduced through clinical trials. Access to the benefits and at times compensation levels may create difficulty in communities or in a different context. Language and complexity of the trials can create a barrier for authentic informed consent (Glickman, et al., 2009). These are just some of the issues raised because they can often increase people's vulnerabilities.

Why the Focus on Women?

There are many factors that justify why the focus on women matters. This paper will focus on one of those indicators that often have a negative impact on many other aspects, ultimately affecting women's wellbeing. In the field of international development, we frequently hear the phrase: "Poverty has a women's face." For women, poverty has many implications —poor health, violence, lack of decision-making power, unfair divisions of work or leisure, ultimately no possibilities of improving one's life. While much progress has been made in the last decade, it has been uneven and many more challenges remain (WHO, 2008). Some would simply argue, women are poor and “die because they aren't thought to matter” (Kristof & WuDunn, 2009, p. 115).

Women's poverty is frequently portrayed within certain geographic boundaries. It is true it may occur in various ways or at different levels within or across countries, but poverty still has a negative impact on women worldwide. In the United States, a study looking at the self-empowerment of at-risk women in healthcare encounters found that "women and minorities have consistently experienced marginalization and inequality in the United States, with low-income, immigrant and refugee women experiencing the most severe forms" (Clifton, Cadzow, & Rowe, 2009, p. 141).

Education often boosts people's levels of knowledge, especially women, and helps build their self-confidence and facilitates access to employment. Individuals are then able to engage in public debates, holding their governments and global institutions accountable by making necessary demands. However, in many parts of the world, women and girls still lag behind in education and employment (WHO, 2008), as illustrated in the graph below.

The book, *Voices of the Poor: Can Anyone Hear Us?*, is a synthesis of the voices of over 40,000 poor people from 50 countries, as part of a World Bank project that aimed to gather the views, experiences and aspirations of men and women who find themselves in the margins of society. An in-depth look at the data on women highlighted that, "women are still disadvantaged in labor markets because children are seen as burdens on workers and women are primarily responsible for their care” (Narayan, Patel, Schafft, Rademacher, & Koch-Shulte, 2000, p. 185).
In many parts of the world, research has shown that education has benefits for health and mortality. The 2013 Human Development Report points out that a “mother’s education is more important to child survival than household income or wealth is and that policy interventions have a greater impact where education outcomes are initially weaker” (UNDP, 2013, pp. 8-9). Kristof and WuDunn argue that “education and family planning also tend to leave families better able to earn a living and more likely to accumulate savings” (Kristof & WuDunn, 2009, p. 114).

Good health links directly to a human’s capacity to contribute to development. Thus, investing in health is a key strategy for achieving poverty reduction. Countries must find ways to address the issues such as burden of disease, like HIV/AIDS, which disproportionately impact women and children more than other populations (Kiiti, 2007).

Empowerment of Women: A Process of Building Capabilities

So research has demonstrated and practitioners have documented many advantages to empowering women (Kristof & WuDunn, 2009). Myers argues that poverty and empowerment need to go hand in hand. He highlights this explicitly when he writes:

The world tends to view the poor as a group that is helpless; thus we give ourselves permission to play god in the lives of the poor. The poor become nameless, and this invites us to treat them as objects of our compassion, as a thing to which we can do what we believe is best. We, the non-poor, take it upon ourselves to name them—homeless, destitute, indigenous, working poor, and so on. Talking about the poor as an abstract noun invites well-intentioned people of compassion to speak for the poor and to practice the latest fads in social engineering. The poor become the custodians of the state, objects of professional study, or a social group to be organized. Whenever we reduce poor people from names to abstractions we add to their poverty and impoverish ourselves (Myers, 1999, pp. 57-58).

In their article, Luttrell and Quiroz seek to explore a wide variety of definitions and conceptual approaches to empowerment. They attempt to frame empowerment beyond the traditional social, economic and political viewpoints, to include human and cultural dimensions as well. They define empowerment as “a progression that helps people gain control over their own lives and increases the capacity of people to act on issues that they themselves define as important” in terms of not only low income, but also social exclusion and lack of access to power, voice and security (Luttrell, Quiroz, Scrutton, & Bird, 2009, p. 10).

Research has revealed that empowering women does often result in positive outcomes. From an international development perspective, “research shows that empowerment can be a genuine public health strategy, and if conceptualized and used effectively it leads to improved community health outcomes and poverty reduction” (Hennink, Kiiti, Pillinger, & Jayakaran, 2012, p. 203).

Implications for Practice and Policy

Interdisciplinary Approach to Learning and Research

Globally, there are many factors that determine and influence our linkage for a local, national and global level—hunger, conflict, violence, trafficking, environmental racism, natural disasters, toxic waste spills, infectious diseases/outbreaks (e.g. SARS, HIV/AIDS, etc), media, climate change, among others. In an increasingly globalized world, these issues are often all interconnected and each has an effect on the others. Because, “the conditions in which people live and die are, in turn, shaped by political, social, and economic forces” (WHO, 2008) our approach to international development must change. Our often narrow, myopic and inadequate approach to health must also change.

In speaking to his fellow public health practitioners, Dr. David Satcher, former U.S. Surgeon General had this to say, “We need a new way of thinking, one where, as public health professionals, we lead by taking an interdisciplinary approach and collaborating across a wide range of disciplines, developing our own workforce to effectively address social determinants of health, and insisting health and non-health policies incorporate a social-determinants approach” (Satcher, 2010, p.7). This is echoed by others.

Paul Farmer, in his book, Pathologies of Power: Health, Human Rights, and the New War on the Poor, effectively argues that human rights work has largely been carried out by the legal field of academia, challenging health practitioners and anthropologists to get more involved. He makes the case in a passionate way:

….as a physician to the poor, I have seen what has happened, and what continues to happen, to those whose rights and freedoms—particularly freedom from want—are not safeguarded. As an anthropologist, I can discern the outlines of many of the ideologies used to conceal or even justify assaults on human dignity …. Human rights violations are not accidents; they are not random in distribution of effect. Rights violations are, rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm (Farmer, 2005, p. 7).

Measuring Development

Additionally, the way development is often evaluated and measured makes a difference in people’s lives. Winner of the Nobel Prize in Economics, Amartya Sen, has very eloquently argued that assessment of progress or improvement in people’s lives must consider whether their freedoms have been enhanced. He highlights some of the conditions that restrict freedom—poverty, tyranny, neglect of public facilities, repressive states, poor economic or educational opportunities, among others (Sen, 1999).

In their book, MIS-Measuring our Lives: Why GDP Doesn’t Add Up, the authors argue that well-being is multidimensional. They suggest that conventional income measures are often misleading because they don’t include all the dimensions of wellbeing. They posit that practitioners must consider the following dimensions simultaneously—material living
to the widening national and global disparities (in health, wealth, and human rights) that now jeopardize human health and survival” (Benator, 1998, p. 295).

We must keep in mind, as Bloom and Canning remind us, "Health is both a direct component of human well-being and a form of human capital that increases an individual's capabilities" (Bloom & Canning, 2003, p. 47). If we are going to effectively engage in a complex world at all levels—local, national and global—than we will need a new way of thinking. It ultimately means policies and practice that are undergirded with social justice, partnerships and advocacy to ensure that vulnerable populations, like women and children, have the capacity to advocate for themselves.

References


Ethics and Research

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Abstract
The author currently is Officer-in-Charge, Navy Bloodborne Infection Management Center, 8901 Wisconsin Ave, Bethesda, Maryland. The views expressed in this presentation are those of the author and do not necessarily reflect the official policy or position of the Department of the Navy, Department of Defense or the U.S. Government. The author is a military service member and this work was prepared as part of official duties. Title 17 U.S.C 105 provides that “Copyright protection under this title is not available for any work of the U.S. government.” Title 17 U.S.C 101 defines a Government work as a work prepared by military service members as part of that person's official duties.

Keywords: ethics, research, IRB, informed consent

Introduction
I would like to start with a brief outline of my talk. First by stating, as I have stated in the past, I am not an ethicist. I am simply a Navy doctor fortunate enough to have had some outstanding research experiences and opportunities in and outside of the United States. I also believe in keeping things simple and plain – at the level that most patients and research participants can understand. So, when asked to speak about “Ethics and Research”, I pondered the following questions. First: “What does it really mean to be an ethical researcher?” I will review some definitions and other opinions about what makes research ethical. Second: “What has your institutional review board (IRB) done for you lately?” Many of my colleagues immediately think of ethics as no more than the IRB and what hurdles they must jump over to get approval to do their research project. Unfortunately, the tone is often strongly negative! I will discuss this briefly and how the IRB can and should be considered an advocate. Lastly, to summarize in my brief time and try to incorporate the theme “From a Dream to a Vision: An Ethical Journey” celebrating the 50th anniversary of Dr. King’s speech, I will discuss the question of “Are we living the ‘Dream’ yet in clinical research?”

Definitions
In thinking about this topic, I decided to step back to the basics initially and review some definitions of ethics. The first definition I found was in a logical place – an old fashioned dictionary – a print copy that is big and bulky in my home library. It was given to me in grade school, and I often enjoyed learning new words from it.

1) American Heritage definition (pg 450, copyright 1970): states that ethics is, “... the study of the general nature of morals and of the specific moral choices to be made by the individual in his relationship with others (aka moral philosophy).”

The second definition was that of applied ethics found in another old fashioned resource – a medical dictionary!

2) Stedman’s Medical Dictionary 6th ed. (pg 339, copyright 1920): Stedman defines ethics as “the science of morality”. In relation to medical practice, the principles of correct professional conduct with regard to the rights of the physician himself, his patient, and fellow practitioners. It further describes within the definition a code of ethics, a set of rules established for the guidance of the medical practitioner in his professional conduct.

Next, to stay contemporary, I checked the definition of ethics on Wikipedia using my iPad.

3) The site was quite detailed yet intriguing: according to Tomas Paul & Linda Elder in Foundation for Critical Thinking – they state that “most people confuse ethics with behaving in accordance with social conventions, religious beliefs and the law,” then define it as a set of concepts and principles that guide us in determining what behaviors help or harms.

The final resource was my medical school ethics textbook, Munson, R. (1992)

4) Munson defines ethics as the “principles that allow us to make decisions about what is right and wrong” bringing us back to moral philosophy, and the application of bioethics where we are specifically concerned with moral principles and decisions in the context of medical practice, policy and research.

Navy Ethos
Additionally, as a Navy officer, ethical values are very important. Our Navy Ethos rests upon core ethical principles and we must always reflect on the five principles of ethical empowerment:
- Purpose
- Pride
- Patience
- Persistence
- Perspective
Plenary Addresses

What does it really mean to an Ethical Researcher?

With the foundation of those definitions and Navy ethos principles, one may ask: “What does it really mean to an ethical researcher?” Or to phrase it alternatively, are not researchers (Physicians, Nurses, PhD scientists, Research Coordinators, Laboratory Techs, Data Management Analysts, Sponsors, military service members, etc.) themselves all inherently ethical persons capable of conducting ethical research studies and never violating the codes set out as law according the Code of Federal Regulations (that is, title 45 CFR part 46, the Common Rule)?

Of course, we know this is not always true. We have countless examples of unethical research including the US Public Health Service Syphilis Study at Tuskegee. Yes, one could argue that the code did not exist during the conduct of that study, so how could the researchers have been held to those standards?

But despite existence for the past 30 years, the code has not totally eliminated abuses. We know that these regulations are intended to protect persons from ever suffering such abuses such as those that occurred between 1932 to 1972. Such abuses included – lack of informed consent, lack of intervention, lack of caring about the death of black men and the impact to their families.

To attempt to answer this question, I engaged in my own self-reflection. I am a researcher –despite never dreaming that I would be doing this work in my life. Did I really understand the difference between right and wrong? What is my moral philosophy?

Being ethical encompasses more than including the boilerplate language required in the research protocol section on “Ethics, Confidentiality and HIPAA” and now HITECH at the back of the document. Being ethical is more than the required elements of the informed consent document, and in the Department of Defense, additional protections restricting research in vulnerable populations such as prisoners and requirements for a medical monitor. Being ethical is more than quoting the regulations and serving on an IRB. Being ethical is certainly beyond passing online annual training designed for biomedical researchers and others who serve in the conduct of research.

What Makes Research Ethical?

Alternatively, Emanuel and colleagues (2000) posed the question "What makes clinical research ethical" with less focus on the ethos of any individual investigator than that of the trial itself. They assume that general ethical obligations such as intellectual honesty and responsibility are in place. They offered seven ethical requirements on the overarching objective to “develop generalizable knowledge to improve health or increase understanding of human biology”. Their suggested requirements are not in response to scandal and are not limited by location. I will briefly highlight each requirement.

Social or Scientific Value

The authors explain that for research to be ethical it must have social or scientific value – ‘the evaluation of the treatment, intervention or theory will improve health and well being or increase knowledge’. Why research something we already know, have treatment for, or fully understand?

It begs the question if so-called me too drug research is ethical? Perhaps we do not need ten identical blood pressure medications. In the area of antibiotic development, this could have the negative effect of fewer products approaching the market as bacterial or viral resistance emerges faster than product development phases.

Social and scientific value requires a balanced approach to scarce resources and non-exploitation. These are the authors’ justifying ethical values.

Scientific Validity

Scientific validity is “use of accepted scientific principles and methods, including statistical techniques, to produce reliable and valid data”. Often we attempt to separate this process from the ethical review per se by having the scientific review prior to the IRB review. Yet we must recognize that the science is not ethical without first being scientifically valid.

Fair subject selection

There is no targeting of “stigmatized or vulnerable individuals for risky research, and the rich and socially powerful not favored for potentially beneficial research”. This requirement highlights the ethical value of justice as articulated in The Belmont Report.

Favorable risk-benefit ratio

Risks are minimized, benefits maximized and the “risks to the subject are proportionate to the benefits to the subject and society”. This is another Belmont principle of ‘beneficence’ along with non-maleficence and non-exploitation.

Independent Review

The fifth requirement to make clinical research ethical is Independent Review - "of the design of the research trial, its proposed subject population, risk-benefit ratio by individuals unaffiliated with the research”. Essentially, this is the requirement for IRB review where the researchers are not involved in the determinations of their own research. Some have advocated that the IRB review should be conducted outside the performing institution perhaps on a federal level. Within the Department of Defense, the use of central IRBs has not been fully supported.

Informed Consent

The requirement for Informed Consent cannot be stated enough – though the authors state it is “necessary but not sufficient” to make research ethical. It is “the provision of information to subjects about the purpose of the research, its procedures, potential risks, benefits, and alternatives, so that the individual understands this information and can make a voluntary decision whether to enroll and continue to participate”. Informed consent respects the subjects’ autonomy to make decisions. It should be free of deceit or deception.
Respect for potential and enrolled subjects

Further emphasizing respect for subject autonomy and welfare, respecting potential and enrolled subjects is a requirement. This is done by: "permitting withdrawal (without the loss of other benefits), protecting privacy through confidentiality, informing subjects of results and new risks or benefits, maintaining welfare of subjects". Researchers have a duty to keep subjects informed throughout the study.

Research in Austere Locations

Research in austere locations adds the responsibility of truly understanding what is ethical and what may not be ethical. Several examples exist that highlight the risk of abusing those beyond our borders.

The opportunities to step outside the inner city where I was raised allowed me to observe true poverty. My first trip abroad included a visit to a humble village near Cairo, Egypt. Here, our team visited the surveillance site intended for a diarrhea vaccine clinical trial. Many children suffered and died of dehydration related to diarrheal illness. Development of vaccine candidates was occurring at our laboratory in Silver Spring, Maryland.

Having visited Cairo very early in my career as an Infectious Disease doctor in training, I did not think about questions such as: Will the research trial cause undue harm? Will the research trial have any direct or indirect benefits? Who will benefit? The subjects, the researchers, the United States, the host nation? Does giving milk and crackers as incentives for a blood draw or taking a stool sample constitute coercion of potential research subjects?

Later in Indonesia, I was similarly privileged and had the unique experience of working in extremely impoverished yet culturally rich urban areas to perform surveillance studies on dengue fever, chikungunya and influenza viruses - all of great importance to the United States military. One of the most common questions from the local health care providers was: Why are we so worried about influenza? "People here die of other diseases; influenza is not as important to us."

I could only acknowledge the observation as correct and had internal feelings of guilt since my influenza funding was the most robust and easily sustained our program’s budget. Thus, I had to identify a reason to make influenza of equal importance to Indonesians. Since my influenza funding was the most robust and easily sustained our program’s budget, it was the greatest thing since sliced bread and you people are keeping me from getting it done!"

We were also challenged in the area of who provides informed consent similar to other countries. Many Indonesian communities have a village head who directs what can occur in the village particularly with respect to foreigners. Permission had to be granted to approach any individual in the community – the concept of informed consent was in fact foreign. No national regulations existed, and we imposed United States regulations to the best of our ability. I was also struggling with implementing the emerging concept of assent for children participating in research.

Indonesia now has several duly constituted IRBs that hold U.S. Federal Wide Assurances. The nation also has trained researchers capable of executing research studies similar to the standards of the developed world.

Collaborative Partnership

The same group led by Dr. Emanuel later added an eighth principle – collaborative partnership – and proposed 31 benchmarks for what makes clinical research in developing countries ethical (Emanuel 2004). These include (excerpts from Table 1):

- Develop partnerships with researchers, health policy makers, and community.
- Involve partners in sharing responsibilities for determining the importance of health problems, assessing the value of research, planning, conducting, and overseeing research, and integrating research into the health care system.
- Respect the community’s value, culture, traditions and social practice. (Example: limitations imposed on the volume of blood collected.)
- Develop the capacity for researchers, health policy makers, and community to become full and equal partners in the research enterprise. (Example: an area of challenge in Indonesia was keeping qualified personnel; capacity building was key to success.)
- Ensure the recruited participants and communities receive benefits from the conduct and results of research.
- Share fairly financial and other rewards of the research.

This publication was published after I had departed Indonesia but our teams intuitively implemented similar approaches to collaborating with our host nation partners. I would argue that the benchmarks dedicated to this principle are ones that can apply even here in the United States.

Moving to my next question: “What has your IRB done for you lately?" I wish to offer the response of researchers to this question from my vantage point of my being, at times, a fly on the wall. At times many would react with great anger (examples: “The IRB is the bane of my existence. It takes too long. What are they talking about; my research is the greatest thing since sliced bread and you people are keeping me from getting it done!”)

As an IRB Vice Chair at two commands, I was either endeared or despised…...endeared for a quick painless, expedited review, or despised for giving would be researchers a long list of questions/comments from the full board and returning the their protocol with “modifications required to secure approval.” The work of any IRB (the Independent Review) is designed to ensure that the research does not violate regulations or codes set forth to protect individual subjects. If you have served on an IRB, you must know the tremendous amount of work involved and hopefully believe that your effort was worthwhile.
As a researcher, I also feel a sense of powerlessness when the IRB has yet to grant approval. This includes those instances when multiple institutional reviews sometimes pose contradictory changes. Waiting for reviews, letters, signatures, stamps on informed consent documents --- all these can get an individual caught up in paperwork mountains that seem pointless.

I applaud recent proposals to reform the regulations governing research to make it more efficient yet still truly protective of individual subjects. Every researcher should be motivated to keep pressing forward in the process to make their research ethical and to conduct themselves ethically (not due to the potential of patents, profits, promotion or fame), but because it is intended to avert another US Public Health Service Syphilis Study at Tuskegee or anywhere else.

Are We Living the Dream Yet in Clinical Research?

Let me proceed to my final question, “Are we living the dream yet in clinical research?” Sadly, I think not. The Tuskegee Legacy Project has elegantly showed that the legacy of the study is not simply that blacks refrain from research participation because of awareness of the study (Katz and Warren 2011). The surveys conducted showed that we (blacks) are equally willing to participate in research and many were not properly aware of the study itself.

However, it is still quite clear that we are ‘not equally’ represented in many areas of research that particularly affect us in greater proportions (heart disease, cancer, diabetes, etc). I believe that the mandate to include “minorities, women and children” appropriately in research trials is still needed, and we have more to accomplish in this area. Recruitment of more minority researchers who may form cultural bonds with communities must continue at every institution involved in the conduct of research, including the Department of Defense. The barrier to minority researchers acquiring NIH grants must be broken and a path to sustained funding resources should be paved.

Conclusion

As I previously shared, the historic election and now re-election of the first African American United States President has indeed been a dream fulfilled. It fuels the hope for more changes in all aspects of life, including improvements in access to affordable healthcare and equity in medical breakthroughs provided via research innovations.

Reflecting for a moment on Dr. King and this stunning memorial, which is near my home, I think about the long journey to get it there. I remember and treasure always his words: “I have a dream that one day this nation will rise up and live out the true meaning of its creed: We hold these truths to be self-evident, that all men (sic) are created equal.”

References


The articles in this section are summaries of select responses to various keynote addresses.
A Response Essay to Joan Harrell’s Keynote Presentation: “Why Are We Here? Communal Bad Blood Perpetuates a Legacy of Mistrust”

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Author Note
This article summarizes the author’s panel response to the ethics and health care keynote lecture of Rev. Joan Harrell on April 2, 2013 as part of the Public Health Intensive Ethics Course at the National Center for Bioethics in Research and Health Care at Tuskegee University. The opinions in this article are those of the author and do not represent the views of the agencies the author serves.

Keywords: community, forgiveness, healing, trust, unconditional love, U.S. Public Health Service Syphilis Study, Tuskegee

Dedication:
To Justice Moving Forward
In addition to honoring my ancestors Rufus Neal, Rueben Neal, and Freddie Lee Tyson, I wish to honor my living relatives whose families were impacted by this study. This heartfelt response is also shared with my husband, Ronald Crutcher, daughter, Sara Crutcher, my parents, Homer Lewis Neal and Rosea Neal Harris, my two sisters Peggy Neal Walton and Jacqueline Neal Blair, my brother Omar Neal, and all their families.

Summary
When I presented my response to Rev. Joan Harrell’s moving presentation titled, “Why Are We Here? Communal Bad Blood Perpetuates a Legacy of Mistrust,” I expected to stick to my outline that I had prepared in advance. But my deep family and spiritual connection to the U.S. Public Health Syphilis Study moved me to speak from the heart. It was the value of listening to Rev. Harrell’s challenging words that brought forth a strikingly different response than expected. The ever-echoing voices of my ancestors Rufus Neal, Rueben Neal, and Freddie Lee Tyson, who were survivors of the study, remind my family and me, that nothing like this study should ever happen again. I, like my family, stand on the shoulders of our forefathers who came before us and risked their lives for medical science. Our relatives were research subjects who sacrificed their lives in order to contribute to what they believed was a worthy cause in health care research. Because of their trust, they were
misled to believe that they were being treated for a deadly disease, when in actuality they were not. Since the conclusion of the study, many generations of African-Americans have mistrusted public health service officials and been unwilling to participate in federally funded clinical trials.

In order to bring back trust within the African-American community, public health officials need to give back and invest positively into the black community. They must be willing to own up to the past and help future generations. Church leaders, public health officials, community leaders, and politicians must engage in ethical ways to gain trust from generations to come. Together, we are called to plant new seeds of hope and harvest new forms of leadership. Religious ministers, especially, should raise the issues that matter most to our community and stand for goodness and righteousness. In order to create healing for all those affected by the study, we have to create a tapestry of hope through education. Our story is an American Story, one of a people of dignity, perseverance, and persistence in spite of the odds placed against us. It serves as a beacon of hope to other vulnerable people who have also fallen victim to unethical and immoral clinical trials. We are somebody in a world in which we have been told that we are nobodies. We are invisible to those who have perpetuated injustice among a people of the darker race.

As a young child growing up in the segregated Deep South of Tuskegee, Alabama, I saw the face of injustice and hatred for a people who sought freedom and justice in the face of prejudice. My father, Homer Lewis Neal, showed what true love is by loving his white mentor during the era of Jim Crow segregation. I learned to love his mentor and family members despite the racism I saw displayed by the majority of southern whites. I learned that this type of love is unconditional, revolutionary, and evolutionary. Rev. Joan Harrell’s presentation reminded me of what I learned early on as a young adult attending graduate school in the Midwest. As humans, we all experience suffering, and can be connected by trust, care, and support. In graduate school, I discovered this truth’s global impact as I learned about the perpetual racism in medicine and other forms of public life that existed among black South Africans during racial apartheid. For me, the syphilis study serves as a multi-faceted approach of how to deal with medical racism and heal from its effects toward a community of people. My male ancestors who were victims of the study have demonstrated that we can love those who have deceived us and others for their own selfish causes. Even after the study’s abrupt conclusion, survivors possessed the greatest strength of pride and dignity. They forgave the medical researchers who did not seek their forgiveness or feel that they committed any wrongdoing.

As an African-American proverb calls forth, “You are, because I am.” Thus, every action, whether ethical or unethical, moral or immoral, affects all people. As an example, the negative consequences of non-treatment of syphilis also affected the wives and children of the victims, when syphilis was transmitted to mothers who bore babies generationally infected with disease. We must be aware that the medical silence of public health officials in not properly informing the male research subjects of their health status also dramatically impacted their family members as well, physically, spiritually, and psychologically. But even more importantly, the lessons of the U.S. Public Health Service Syphilis Study teach us that human values, virtues, and visions are common to all people, both locally and globally. We are, in essence, one human family, inextricably connected to one another. There is a destiny that makes us a family of one accord. No one goes his or her own way alone. Whatever we put into the life of others, whether good or bad, affects and comes back to our own life. I have discovered that love is the one virtue that creates healing from wrongdoings. We must be bold and brave enough to promote a culture of trust rather than a legacy of mistrust. We can perpetuate hatred or we can serve as seeds of hope for greater healing and redemption, as our ancestors have done. The choice is ours to make. But as for my family and me, we choose to celebrate the love that is within us in order to break the chains of medical mistrust and renew the values of forgiveness and healing.
Disruptive Spheres of Ethics: Doing the Work of Rescuing, Reclaiming and Rehabilitating Ethical Thinking

A Response to the Plenary Keynote Address of Dr. Lucius T. Outlaw, “From Deep in the Black Belt, Rescuing Reason/Reasoning for Ethical Work: Evolving Spheres of Ethics”

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Author Note
This article is based on a presentation made at the 2013 Public Health Ethics Intensive Course in response to Dr. Lucius T. Outlaw’s presentation, “From Deep in the Black Belt, Rescuing Reason/Reasoning for Ethical Work: Evolving Spheres of Ethics.” The opinions herein are solely those of the author and do not represent the views of any of the institutions the author serves.

Abstract
This presentation illumines how several predominant spheres of ethics, such as feminist, womanist, liberation and black liberation, began as direct responses to Reason’s promiscuity in service to multi-dimensional (race, class, gender) oppression that Dr. Outlaw discussed has resulted in various spheres of ethics. This presentation will illumine how several predominant spheres of ethics, such as feminist, womanist, liberation and black liberation began as direct responses to Reason’s promiscuity problematic behavior and institutions within society, this reclaiming and rescue work is imperative. It is precisely this rehabilitative ethical work that has resulted in various spheres of ethics such as womanist, liberation, feminist, mujerista, and black liberation ethics, to name a few. The significance of these spheres of ethics is that reason is put in service of reclaiming the humanity of marginalized vulnerable populations and their reasoning poses a challenge to the epistemological and ontological assumptions of not only moral philosophy but points to gaps in the nation’s cultural meta-narrative. The philosophical enterprise, historically guarded and managed by white males, has left the life experiences of Hispanic, Native American, Asian American, poor persons, and women—“othered” people (not white male), invisible. Therefore, legitimated ways of knowing and being developed through exclusionary practices that reinforce the powerlessness and invisibility of “othered” people. However, white women, black women and men, Native Americans, and Latin Americans, who grew weary of this invisibility and silence breached social propriety with feminist, womanist, liberation, mujerista and black liberation ethics. These spheres of ethics do not say that women, racial and ethnic minorities are more important than white men, but that they are just as important. For example, feminist philosophy attests to the fact that only half of the American experience and story has been told.

Feminist Ethics
Feminist ethics is concerned broadly with questions of justice, equality, rights, dignity, and autonomy of women, arguing against the dominant gender-neutral conception of these moral categories. Feminism, like womanism, liberation and black liberation theology and ethics, is not defined solely as an intellectual commitment but moves beyond theory to praxis. Indeed, an important aspect of feminism is the political movement, from the nineteenth century on, seeking justice for women and an end to sexism. This brief overview of feminist ethics will highlight three of its many features—that it is international; begins with concrete situations; and presupposes autonomy of women. This cursory overview of
feminism will not detail the diversity found within feminism and thus, feminist ethics. There are various feminist social-political theories which undergird the analysis of the oppression of women and determine the normative stance of ethical reflection, such as: Radical Feminism, Marxist-Leninist Feminism, Sex Roleism and Socialist Feminism, to name a few. Among these various feminist theories, there are divergent normative positions regarding the analysis of the origin of women’s oppression (Robb, 1994); however, the starting point of ethical reflection is virtually constant—concrete situations or lived experience of women. This starting point resists and challenges the traditional starting point of western philosophy which abstracts individuals from concrete situations, especially situations of oppression. This point of departure challenges the gender neutrality found in historical western philosophy.

Violations of women’s human dignity merely because of their gender cuts across social, economic, political and religious institutions in society. “Many women all over the world find themselves treated unequally with respect to employment, bodily safety and integrity, basic nutrition and health care, education and political voice.” (Nussbaum, 1999) Therefore, one of the main features of Martha Nussbaum’s and other feminist theorists’ conceptions of feminism is the significance of it being international. This feature of both feminist and womanist ethics is significant as it brings to the fore the common ground of concrete experiences of the oppression of women globally. This aspect of feminist ethics particularly allows for a significant analysis of the economic forces that constrain women’s autonomy. Thus, issues of women’s economic dependency in the family; inequalities in the structure of employment, pay and promotion; the division of labor between the sexes; and other contributing factors to the feminization of poverty are emphasized. For example, in her study of the challenge of women’s poverty to Christian ethics, Pamela Brubaker argues that the inadequacy of poverty analysis and policies around the world lies in their inability to touch the reality of a significant portion of the global population—poor women. The problem is with “presuppositions which render women’s material and cultural realities invisible.” (Brubaker, 1994)

Economic inequality and economic injustice are moral issues that have inadequately addressed the suffering of women. The issue of moral status is intimately related to the inadequacy of these phenomena. Historically, the moral status of women has been intricately and especially tied to their economic fate. The economic inequality and economic injustice endured by women globally is tied to the fact that the requirements for justice have been derived apart from analysis of the concrete suffering of women, as well as from “reason abstracted from history, and faith compromising with history.” (Lebacz, 1986) Feminist social ethicists call for a rehabilitation of ethical thinking regarding the lived experience of women. The first, and most significant, step is to not only give epistemological privilege to women broadly, but to account for the suffering of poor women, particularly, in both economic and theological analyses. (Brubaker, 1994) This intersection of multi-dimensional oppression is particularly observed in the lives of women of color. It is womanist theology and ethics that focuses on the coalescence of the injustices of racism, sexism and classism in the lives of women of color.

**Womanist Ethics**

Womanist theology and ethics developed in response to feminism’s neglect of the multi-dimensional oppression that faces African American women as well as in response to earliest forms of black liberation theology and ethics which had a blind spot when it came to dealing with sexism. Race, gender, and class have been mechanisms of social stratification, historical bases of discrimination, sources of injustice, and thus hindrances to human flourishing. Black women stand on the margins of society, and at the intersection of race, class, and gender. Though ethnically and culturally situated, “unlike feminism, and despite its name, womanism does not emphasize or privilege gender or sexism; rather it elevates all sites and forms of oppression…to a level of equal concern and action.” (Phillips, 2006) By virtue of its emphasis on various dimensions of oppression, part of the significant “rescue work” performed by womanist ethics is its attention to the material and cultural reality of poor women of color around the world. There is a concern with international culture, as well as global politics and economics. (Phillips) However, like black liberation, womanism has been criticized for being largely an intellectual commitment; however, it is also rightly conceptualized as a social change perspective.

The starting point for womanist ethics is the lived experience of black women, but it does not “begin and end” with women, as some of its features highlight. The key features of womanist ethics emphasized in this cursory overview are those stressed by womanist scholar, Layli Phillips. Phillips argues that womanism is vernacular, communitarian, and spiritualized. (Phillips, 2006) The feature of being “vernacular”—being associated with everyday people and everyday life (Phillips), speaks to the heart of womanism. It is grassroots and identities with the “masses”. Phillips contends that, “masses” does not suggest opposition between the “masses” and “elites” but underscores the reality that all people have ‘everyday’ lives and concerns that connect them. Common concerns that unify humanity include: “food, shelter, relationships, communication, body and health, love, life, death, and contemplation of the transcendental…” (Phillips) Womanist ethics is thus concerned with social justice, not just for women, but for the masses. The concern is with the just distribution of not only resources but power; that institutions are structured such that humanizing relationships between groups and individuals are fostered and contribute to positive well-being of all. This communitarian emphasis on the well-being of all—emphasis on the commonweal or “the optimization of well-being for all members of a community” is the goal of social transformation. (Phillips) This emphasis on community has various strata: black women—at the level of self-identity, the black community, other oppressed people, and ultimately all of humanity. (Phillips) In this notion of commonwealth is included the environment and the Transcendent—creation in totality. Womanism thus seeks to reconcile relationships—between not only people, but between people and the environment as well as between people and Spirit or the spiritual realm. (Phillips) Thus, one of the significant features of womanism is that it is spiritualized. In this conception, human life, the material and spiritual world are intricately linked. Thus, social justice activism is informed by spiritual beliefs and practices—the belief is that “spiritual intercession and consideration of the metaphysical dimension of life enhance and undergird political action.” (Phillips)

This brief overview of womanism drew contrasts and similarities with feminism. Both are involved in the “sacred ethical rescue work” Dr. Outlaw discussed. Both seek the destruction of dehumanizing ideologies, economic and social inequality, and unjust institutional practices that diminish human flourishing for all people. Another significant common feature of both feminism and womanism is the concern with embodiment—the concern with bodies. A criticism often lodged against western philosophy is not only its
plenary responses

abstraction from concrete suffering of “othered” individuals, and its dispassionate, disengaged stance but its lack of attention to embodiment.

from the inception of this nation, the use of black bodies as property, and the scientifc and theological justification of such use were grounded in the perception of the moral status of african americans. the historical denial of full moral status has calcified into cultural stereotypes that have been etched into the historical memory of americans. these stereotypes are subconscious and continue to affect the way black bodies are viewed and treated. the misconception of black bodies as objects during slavery fed into the continuous transgression against these sacred (made in the image of god) bodies in medical experiments post-emancipation. indeed, african americans provided “clinical material” for early hospitals during the nineteenth century. these early hospitals were not institutions for healing but places where physicians could be trained and practice experimental approaches—conducted on black bodies as well as the bodies of the poor. the historical understanding of these bodies was that they provided needed clinical material upon which diagnosis, treatment and dissection could be practiced. (Washington, 2006) “Because of widespread use of blacks as teaching material, new physicians left their medical school training with a deeply ingrained habit of looking at blacks as demonstration material and experimental objects.” Thus, biomedical violations such as the syphilis study could continue to persist without public outrage.

the humanizing rehabilitative work that these spheres of ethics—womanist and feminist do, has far reaching implications not just for the self-identity of “othered” members of humanity but for the way that we view one another—for the way that we understand our relationship to one another and the moral claims that we make on each other. the humanizing moral values of respect, dignity and compassion rebuild collective identity enabling survival and flourishing of “others”. other spheres of ethics that have engaged in this rehabilitative work are liberation and black liberation theology and ethics.

liberation and black liberation theology and ethics

both liberation and black liberation theology and ethics evolve from particular socio-historical contexts. the starting point is what is happening in the lives of people weighed down by the burden of economic, social and political suffering. both begin with praxis—with the struggle for liberation of those experiencing social injustice and exploitation. the origin of liberation theology and ethics is within the socio-historical context of colonization in latin america—and religion’s significant role in human subjugation and exploitation. in latin america, liberation theology was not just a set of theological ideas and beliefs, it was also a movement and the theology evolved as a reflection of the actual movement for freedom from oppression. (smith, 1991) for liberation theologian, gustavo gutierrez, the task of theology is to reflect critically on what is actually happening in history. this way of doing theology begins in latin america but is universal in its application. thus, theology may begin with reflection, but goes on “to be part of the process through which the world is transformed.” (zweig, 1991) therefore, liberation ethics will include in its analysis the material reality of laborers, peasants, unemployed, women and similarly situated “othered” individuals.

according to theologian Dwight Hopkins, the hearts and minds of enslaved africans who resisted the identity based on “Christian” sanctions of slavery imposed on them by european americans was the womb from which black liberation theology was birthed. therefore, “slave religion provides the first source for a constructive statement on a black theology of liberation.” (Hopkins, 1993) The evolution of black liberation theology took place steadily as enslaved africans fought to survive sub-human conditions and economic exploitation, gained their freedom and continued to fight for equal citizenship rights and privileges. Black liberation theology was nourished in the ethos of self-determination and self-help that was present before Emancipation. As an intellectual expression, black liberation theology, therefore, arose from the blending of Martin Luther King’s gospel of racial justice; black power’s message of black pride, self-determination and racial solidarity; and a long tradition of self-help, social uplift; and black nationalism. (Hopkins, 2005) Black liberation theology was an attempt to make sense of being black and Christian in a society that denigrated black people and their culture, and in an american religious context rife with racism.

A significant feature of liberation theology as it developed both in Latin America and in the throes of the black struggle for freedom and justice in the U.S., is the centrality of God’s relationship to the oppressed. According to James Cone, “Yahweh is the God of the oppressed and God’s revelation is made known only through the liberation of the oppressed.” (Cone, 1999) Thus, leading to another important feature of liberation and black liberation theology, that “salvation” transcends its meaningfulness for the spiritual life and includes justice—social, economic and political justice. The intention is that theology is not used to justify oppression but to destroy it. Thus, liberation and black liberation theology and ethics have an eschatological vision, the goal of a “new earth” and new persons—social revolution, not social reform, is sought. The ethical analysis, therefore, is grounded in Marxist analysis—analysis of social conflict and class struggle. Indeed, liberation and black liberation are spheres of ethics grounded in theological responses to the promissucity of reason in service to oppression.

conclusion

the various spheres of ethics discussed in this presentation have been disruptive to the western philosophical enterprise. they are disruptive precisely because their reclaiming and rehabilitation of ethical thought says that the lives, experiences, knowledge of “othered” people matters. Not only do these lived experiences matter, but they are important epistemological sources for shaping how society should be ordered. therefore, when the questions of what justice requires and what justice permits rise, these various spheres of ethics are available to empower society to use white women, black women, latinas (mujeristas), native americans, black men, Asian americans, and poor persons as meaningful epistemological sources to answer the questions of what social justice requires. as we learn to listen to those who have been historically silenced, and learn to see those who have been rendered invisible in our cultural cannon of knowledge, we will help them reclaim their worth and dignity. when others are not invisible, when their humanity is respected, they are less vulnerable to atrocities such as the bioethical violations that took place in the syphilis study. because the men who participated in that “study” were of no value to those in power, because they were black, southern, poor, sharecroppers, they were understood to be expendable. This is why it is important to heed the call of these disrupted spheres of ethics—the call for inclusion, equality, and justice for all. these various spheres help call us back to the fullness of who we are as a nation. we are a nation comprised of diverse experiences and
varied forms of knowledge that can be reclaimed and brought into our cultural cannon and public transcript, underscoring the fact that we all matter, that we all are of worth and most importantly, that we all should have a say in how society is ordered. These disruptive spheres of ethics call us to come to terms with how far off the mark we are when it comes to justice for all, they keep us honest about where we really stand in relationship to what is right, good and just—and often we fall short, but these disruptive spheres of ethics also offer us hope of being and doing better.

References


Author Note

This article is a post-event reflection summarizing the author's response to the ethics and health care keynote presentation of Dr. Lucius Outlaw on April 2, 2013. The original keynote address and the author's original keynote response were part of the Public Health Intensive Ethics Course held at Tuskegee University in Tuskegee, Alabama under the sponsorship and direction of the National Center for Bioethics in Research and Health Care. At the time of the original presentation, the author was a federal employee. As required at that time, the author obtained the required permission for his presentation from his respective senior authorities. To meet standard requirements for the permissions at that time, it is certified here that the opinions in this article are those of the author alone and do not represent the views of the United States Government, the Department of Defense, the Department of the Navy, the Uniformed Services University, or other agencies the author has served or continues to serve in any fashion. Finally, since the article was, at least in part, developed during the author's federal employment, it is dedicated therefore to the public domain under the Copyright Act.

Keywords: human freedom, human desire, addiction to power, moral objectification, paradigm shift

Introduction: The Pulse Within

In these past months, I have been moved to considerably deep levels of personal reflection after having heard and first responded to Professor Lucius Outlaw’s keynote address, “Evolving Spheres of Ethics.” Even during Professor Outlaw’s actual presentation, something kept stirring in me at the very deepest personal levels. At first, I thought it might have been my own intellectual curiosity as an academic theologian and one who teaches in the broad field of the healthcare humanities. At other moments, I thought I might have been caught up in some of the wonderfully vivid images that Professor Outlaw conveyed. However, as I have come to understand in these last months, something deeper was being moved and urged. It all seemed to center on one word, “Freedom.”
A few weeks after the 2013 Public Health Ethics Intensive had concluded, Richie Havens, the famous American musician, passed away. That was on April 22, 2013. Since then, it became clear to me that the figure of Richie Havens and his extraordinary musical legacy were central to what was being pulled up inside my own self.

On August 15, 1969, Richie Havens was the opening act of the now famous Woodstock Concert. Due to the delay of other performers, his opening act was long extended. He eventually played and sang his now famous “Freedom” that combined his exquisite guitarist talents with the words of the spiritual he had sung as a little boy, “Motherless Child.” In a much later interview, Richie Havens commented on what had occurred inside him that caused this now famous performance to emerge so artfully and so extemporaneously. He said:

“I think the word ‘freedom’ came out of my mouth because I saw it in front of me. I saw the freedom that we were looking for. And every person was sharing it, and so that word came out. (Havens 1972).”

I remember that scene quite well from my now long gone youth. I was going into my senior year of high school. And I remember watching this scene on the news in the living room of my family’s home in the Italian Market of South Philadelphia. I remember watching; and, today, I remember that at that time I was filled with an amazing mix of confusion and contradictions of thought, images, and feeling.

In that period of my life, I would not characterize me in any way as being an open person. In fact, I humorously portray myself as one of the most closed individuals I had ever known in my then brief 17 years of life. Yet despite all of my calcified positions as one whom at 17 thought he knew and possessed the truth, I recall today very clearly something very important. For as I watched Richie Havens and sneeringly castigated those who had gathered at Woodstock, I remember my foot tapping, my head nodding, and my heart racing all so unexpectedly. What in the world was going on inside me? How could I, of all people, have been seemingly drawn into the music and color of what was going on around me with such progressive beats? Sure, I was raised as a musician in a musician family. But how could this “modernity” be moving me to sway to the music?

Something different was going on inside me for sure.

While filled with my own clinging to what I believed to be the truth, the melody of “Freedom” was tapping inside me. In fact, it was doing far more than tapping. For as I reflect on the next decade of my life after that moment, I believe I have a better understanding of something far deeper that was emerging inside. Inside me, just like it does for every human being, there is the quest, the urge, the passion for Freedom itself --- a passion that is at the heart of what makes a people risk everything they have so that they might achieve that which they could be.

Not so long ago, I found this sense of Freedom wonderfully addressed in terms of the history of the African American community in what is today the famous historical analysis of Isabel Wilkerson. In describing the pathway of the Great Migration that former slaves journeyed to new lands and opportunities beyond the traditional South, Wilkerson movingly addressed the power that pulsed beneath the footsteps of those who trod the road. It was not a road built upon political power. It was a pathway made possible because of the courageous choice to be free. Indeed, as she describes so well, those who left the South in search of Freedom knew well that the journey would require a sense of courage that was strong. Such is what is needed when one wants to make their Dream come true. It means taking one’s destiny into one’s own hands not because one is making a supple decision between variables. Rather, the choice for Freedom is the ardent passion of what a people must choose because it is the essential ingredient of their very nature. As Wilkerson says so well of the Great Migration:

Over the decades, perhaps the wrong questions have been asked about the Great Migration. Perhaps it is not a question of whether the migrants brought good or ill to the cities they fled to or were pushed or pulled to their destinations, but a question of how they summoned the courage to leave in the first place or how they found the will to press beyond the forces against them and the faith in a country that had rejected them for so long. By their actions, they did not dream the American Dream; they willed it into being by a definition of their own choosing. They did not ask to be accepted but declared themselves the Americans that perhaps few others recognized but that they had always been deep within their hearts. (Wilkerson, p. 538)

When Professor Outlaw presented his scholarship, the vibrance of his message clearly was founded upon the search for freedom that is central to the pilgrimage of each human person, community and population. Indeed, freedom is inherent in the very nature of what it means to be human. Perhaps even more fundamentally, freedom is at the heart of life itself in every form. As I have reflected these past months upon how Professor Outlaw guided us into the metaphors of the human individual always bursting out of discrimination and devolution, the images that keep welling up within me are those of courageous women and men who refuse to be chained by the many forms of dehumanization, both explicit and implicit, that we humans so tragically impose on each other. Whether between members of any race or ethnic group, between genders or those of diverse sexual orientations, between those of any religious groups or other affiliations, the processes of dehumanization are a constant terror in our history. The bursting out of these processes is not something just political or theoretical. They are not just social or cultural. They are not just about being free to do what it is we want. Rather it is about our inherent and non-negotiable ability to “be” who we are and all that we can dare to become as other-oriented, selfless, and generous beings in an existence that is not predicated on fear and domination. This is the passion that is at the heart of what it means to burst out of the restrictions and limitations that Professor Outlaw so artfully addressed when speaking about how human self-centeredness restricts reason and human thought.

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Plenary Responses

Just like the constant strumming of Richie Haven’s guitar and his singing the word itself, Freedom is an internal pulse that moves the human person and the human community to dream beyond the present, hope for what might be, and summon the courage to turn dreams into waking realities. Freedom is that pulse inside the mind, the heart, the spirit, and what opens up hands to become fists that can crush the shackles of every form of injustice that keeps the human person enslaved in “the less than.” It is the ultimate “Desideratum” or “Desire” of our very existence.

The Problem of Power

But from the discussion above, a seriously important question emerges: If it is the nature of the human person and human community to be free, if this is in the nature of each of us, why is it that some would seek to enslave me? What is it within the human individual or collective psychology that would motivate me to make choices that would deny to others that which I am myself also seeking and needing?

We have only to remember some of the more recent tragedies in American healthcare and research history to see what is at the heart of it all, namely the problem of power. In fact, the problem of power is more than just a “problem.” It can rightly be seen as an addiction. If anyone would doubt the massive addiction that power is, we need only to recall the absolute horrors of the Holocaust so as to remember the depths to which the human person can sink. How horrific that a people who in 1931 could say that the disadvantaged were not to be exploited in research would eventually see any individual be exterminated because the Nazi regime did not accept them as even human (Field & Berman, 46). Right here at home, we need only recall in our own nation the absolutely horrific inhuman exploitation at the heart of the USPHS syphilis study and the follow-on actions perpetrated by some of the same government doctors on the people of Guatemala.

Outside the realm of healthcare or medical research experimentation, we look to the horrific tragedies of domestic violence, the slaughter that took the lives of the children of Newtown, the unspeakable tragedies of sexual assault and rape, the nightmare of poverty, or the refusal of our society to provide food and healthcare for the poor and underserved.

We are not creatures who seem to care about the freedom and respect due every person. Something within us seems to make us deaf to the cries of the poor and those whose need for freedom and equality is the same as our own.

A number of years ago, the work of the philosopher Nicolas Berdyaev on moral objectification was presented at a national academy meeting. That original work was recently reworked into a more formal publication. In both texts, when the authors discuss why individuals turn human “subjects” into “objects,” we find a summary that may help us to reworked into a more formal publication. In both texts, when the authors discuss why individuals turn human “subjects” into “objects,” we find a summary that may help us to reworked into a more formal publication. In both texts, when the authors discuss why individuals turn human “subjects” into “objects,” we find a summary that may help us to reworked into a more formal publication. In both texts, when the authors discuss why individuals turn human “subjects” into “objects,” we find a summary that may help us to reworked into a more formal publication. 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especially under a very intense and extremely insightful supervisor with a group of fellow students who would be unbelievably demanding of each other.

And the setting for what I had hoped would be an easy nine credits to graduation? A mental asylum on a several thousand-acre property with an intense pastoral care program!

The summer of 1978 was far more than I ever could have anticipated.

That summer’s intensity was made even more intense by my own self-definitions at that period of my life. I had not yet outgrown the calcified portrait that was my own self much as I discussed in the introduction above.

One day, I had been assigned to lead a spiritual event in the various buildings whose wards I was serving. At that time, I was the student chaplain for three units of adults and the one adolescent unit. On this particular occasion, without any forethought or care or understanding of how my patients would react, I decided to dress in full worship robes. Not a very wise thing to do while serving the needs of those who were suffering from visual and auditory challenges. As I was making my way past one of the buildings dressed in full white flowing vesture, a female patient was sitting on the curb outside watching me glide in full regalia past her to the entryway. In addition to her mental challenges, she was a morbidly obese person. She neither shaved, nor bathed, nor wore undergarments. She sat on the curb with “full visibility” wearing a torn-open sleeveless dress. In her fingers were the burnt out stubs of cigarettes she had smoked earlier that day. Sharing my own ethnic and regional heritage, she looked at me and screamed (but peppered with the most colorful street language which I shall, for this text, omit):

“Hey you, what are you? Are you some kinda angel?”

I looked toward her. Instead of shaking in my own boots, I tragically (today, comically!) decided that this might be the perfect moment for me to make a convert. I went over to engage her, and used some of the most thoughtless pietistic nonsense such as “My daughter.”

The woman just kept asking, “I asked you a question. Are you some kinda angel? Why won’t you tell me what you are?”

The dialogue went on for a while. Finally, exasperated as she was with me, she finally said, “OK, I get it. You’re some kinda student. OK. So what’s your name?”

I answered; “Brother Gabriele.”

It took no more than one split second. The woman flailed her arms and screamed at me.

“You call yourself a chaplain. You lied to me! You told me you weren’t an angel. And now you tell me your name is Gabriel!????”

She screamed.

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I ran.

I immediately went to my supervisor’s office and told him what happened. Smoking his own cigarette and flicking his ashes on the floor, he took a deep breath and asked me in true CPE-style, “So why was this story important for you to come tell me? You didn’t do anything really wrong and I know that. A little stupid, but not really anything wrong. So, why did you need to tell me what happened? What’s the importance of what happened?”

I was stunned. I stammered. I sweated. I had no idea why he was asking me what I thought was an insane question. And it was then that he inched slowly toward me and stared at me directly into the eyes.

“Oh this story is very important to you, son. V-E-R-Y I-M-P-O-R-T-A-N-T.”

I was in shock. He went on.

“You see, son, you went walking around the property today dressed up as if you are an angel. You’re not. In fact, that woman? SHE was the angel. And why was she the angel? Simple, this woman asked you the most important question of your life: ‘Who are you?’ and stung your conscience good.”

I found out afterward from her file that the woman’s first name actually was Angela.

Amazing. Angela --- the real angel after all.

Today, I smile and keep the story and image of Angela the Angel on the Curbside ever before my conscience. Every time I think through what I am doing with my life, I keep thinking back to this one angel who impacted my very self. Every time I think through how I might be tempted to power or to deny others their own dignity, I recall the unseemly and unkempt Angel on the Curbside who reminded me then and who reminds me now who I am and what I am called to do for others.

Moments such as these are critically important in our lives. They are essential if we are to resist the temptation to power and avoid turning ourselves into a Gollum figure. This is as true for us as individuals as it is for us as societies, nations, and institutions. If we are to resist the problem that is the prostitution of human life and dignity that occurs with the addiction to power, it seems that the first lesson we must learn is how to stay poised to change.

Thomas Kuhn, in his famous scholarship, addresses how human history advances through the discovery of the unexpected. He demonstrates that the changes of human history that result are extremely complex and interwoven within a multiplicity of intricate factors that require careful review and reflection. The results of such events are a series of eruptions that are themselves intense and create monumental changes from the former order of things. (Kuhn, pp. 92ff). These are the “paradigm shifts” that occur and make for the real revolutions of life. The old passes away. Something new is born. And in effect, this is the way in which human history itself progresses. It is also the way our individual histories progress as persons. You see, it is the very rhythm of life itself.
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It seems then that the call to change itself is the first step in addressing the addiction to power and how that addiction prostitutes human life and the dignity and equality of human individuals, communities, and cultures. None of us is “better” than the other. None of us can encapsulate the Truth within the self that is the individual or race or gender or any other category. One engages in power each and every time that we do not hear the Angelas of this life calling us to remember who we are in unity with all other beings and what we are called to do, especially in raising up those who are bowed down. In other words, as in a recent article on LeaderBeing in professional life, one of the most critical postures we must take at every moment of our personal and corporate histories is to stand ready to be “catapulted” into new understandings of what is the Truth about ourselves and about our unity with those with whom we share this planetary existence. (Gabriele & Caines, pp. 17-18.)

Indeed, in our lives we know and see the harsh histories of what occurs every time that we keep ourselves from being catapulted into the equality we share with every other human being. We see the misery that has been created every time we have allowed hatred and fear to make others less than ourselves. History is replete with so many examples. Some of them have already been mentioned in previous paragraphs. In remembering them, however, we do damage when our rightful anger over the past keeps us from seeing what it is we need to do today to avoid such problems from happening again.

On September 11, 2012, the Smithsonian Annual Ethics Education Series featured a world premiere of the 2007 Hartfilms/PBS documentary, Sisters of Selma: Bearing Witness for Change. The film is a historical presentation of the six Roman Catholic nuns who dared the restrictions of their time by walking in non-violent civil rights protest against the horrors of what had occurred on Bloody Sunday, March 7, 1965, in Selma, Alabama. The sisters suffered afterward. Amazingly, they were — even at that time --- proud of what they endured as a result. Each of them went on to lead other social justice causes of the times. They continue to do so today. One of them, Sr. Mary Antona Ebo, was one of the panelists at the Smithsonian premiere. At this event, she was in her late 80’s. She was an amazing speaker. While the participants enjoyed meeting her, we all were stung by her call not to let our misery over the past keep us from taking up the challenges of social justice today. As she said on that occasion about her own experience in Selma and afterward. “You know, I get tired of talking about Selma in a way because there’s so much more that’s going on around us today that needs to be addressed.” (Sr. Antona 2012)

Indeed. Sr. Antona calls out to us today. As we remember the horrible tragedies of what has already occurred in our midst, our grieving over “back then” cannot overwhelm us from hearing today the cries of those who scream out to us in the night for freedom and dignity. We cannot hide behind politics, or policy, or politeness. We cannot be stuck in our anger over the past (understandable as that truly is). We cannot allow fear today to keep us from confronting the prostitution that is the addiction to power. It is our challenge and call to resist the temptation to power such that a Holocaust, or a Newtong or, any other horrific tragedies of human hate and dispossession will never again be able to deprive others of that which is the right of every human person to dignity, equality, justice, happiness, and peace.

Conclusion: The Call — Ever Ancient, Ever New

From the early centuries of the Common Era onward, Augustine of Hippo has been studied as one of the great Western philosophers. Son of a Roman patrician father and an African mother, even the most cursory reading of his many works reveals an utterly human individual who was haunted by his own ghosts and fears. A man of his times, he sipped from the wines of many philosophies and life stances, and is pictured very accurately as a man who never seemed to be able to settle into life with any sort of normalcy. He was the consummate experimenter, the consummate questioner, the consummate spirit that could never know the meaning of satisfaction.

Yet there is one scene of his life, found in The Confessions, where he seems to find that for which he has sought with all of his strength. For Augustine, that was the figure of his God. After a long and lifetime search, he seems to have discovered that “Other” for whom he longed all his days.

Late have I loved you, Beauty so ancient and so new, late have I loved you! Lo, you were within, but I outside, seeking there for you, and upon the shapely things you have made I rushed headlong — I, misshapen. You were with me, but I was not with you. They held me back far from you, those things which would have no being, were they not in you. You called, shouted, broke through my deafness; you flared, blazed, banished my blindness; you lavished your fragrance, I gasped; and now I pant for you; I tasted you, and now I hunger and thirst; you touched me, and I burned for your peace. (Book 10, Chapter 27).

Regardless how one may wish to judge the object of his words or his conceptions about the same, what is of so much power is the fiery passion within Augustine that is revealed --- a passion for that which is true and gives him the meaning of his life. This was his search to find that “Other” that would fill up the emptiness within. I identify with Augustine’s words at one of the deepest levels of my own being. I would daresay we all do. For at the heart of what we read above, if we listen within us we have the same passion. It is the same search that we all share. In fact, it is the same desire already discussed in the previous pages.

The question arises, however: If it is the same passion and the same quest, what is it that makes an Augustine an Augustine and not be turned into a Gollum? How can we in our own day ensure that the desire we have within us also does not lead us to the addiction and prostitution of power where a Holocaust or a Newtong is possible? What image can keep us being catapulted into the right direction so that we raise up the poor and ensure that no human being is ever enslaved again for any reason anywhere at any time in our age or in the ages to come?

In the last two years, an amazing gentleman named George Brummell changed my life. A retired Army Staff Sergeant, George is the former National Field Director of the Blinded Veterans Association. George was born and raised in a terribly racist part of the East Coast. He was blinded in Vietnam by a landmine explosion on June 6, 1966. I first met George at Walter Reed National Military Medical Center in August 2012. At that time, I
read his memoirs, *Shades of Darkness: A Black Soldier’s Journey Through Vietnam, Blindness, and Back*. I finished it in one sitting and nearly had the book fall out of my hands when scenes from his own childhood mirrored scenes I recalled from other parts of Augustine’s life. I came to know the suffering that George had known in this life. And I marveled at the way he has become a national and cultural leader. Most of all, I am deeply grateful for how his friendship has transformed me.

In 2013, George authored a new book, *The Mole and the Violin*. It is a children’s book on blindness. It resulted from his current work going to grade school classes in his area to teach children about blindness and how blind persons are not disabled, but rather “diversely abled.” It is a profound work and one that I treasure. One of the scenes at the end of the book comes to mind as I bring my thoughts in this reflection to closure.

*The Mole and the Violin* is the story of Mikey the Mole who emerges from the underground with his lack of sight and meets Emma, a young girl who is a violinist. They become friends. And through a variety of actions, Emma gets her grandfather to carve for Mikey a miniature violin. She teaches Mikey to play. The music they create is amazing. It changes them both. At the end of the work, you meet another of Mikey’s friends, Shalonda the Mouse. Mikey gets Shalonda and Emma to meet. Different as they are with all the prejudices mouse and human have about each other, Mikey gets them to be friends. One of the final exchanges between Emma and Shalonda is very revealing for us. This is the scene where Emma and Shalonda first encounter each other.

"Can you make her go away?" she (Shalonda) whispered to Mikey.

"Why?" he asked. "She’s my friend."

Shalonda shook her head and said, "I know, but she’s a human. They don’t like mice."

"I’ll bet Emma likes mice," Mikey said and shouted up to her, "Hey, Emma! You like mice, don’t you?"

It wasn’t exactly the truth, but Emma said, "I think mice are just adorable, and I would really like to meet your friend."

Emma’s words changed Shalonda’s attitude completely. She decided that maybe not all humans were mean; this one, at least, seemed nice. "How do you do?" she said as politely as she could. "It’s a pleasure to meet you."

"It sure is!" Emma said. "I’ve never met a mouse before, and I’ve never heard of one who could talk."

"Oh, we all can talk. It’s just that most people don’t bother to listen. They assume we can’t do anything but steal cheese."

"I promise never to assume anything about mice again," Emma said.

"I’m so happy!" Mikey cried out. "I’m with my two best friends in the world." (Brummell, p. 76).

What a fascinating and wonderful image for us to keep at the center of our thoughts and lives! Here we find two creatures brought together by one “diversely abled” but who had learned almost miraculously how to make the most beautiful music in the world on a violin. Yet Mikey’s greatest music was not what he bowed on the strings of a miniature violin. It is what he caused to be strummed from the heartstrings of those who had previously feared each other. One didn’t know the other could talk. And the other didn’t think the one would care. A miracle happened. Such is what happens in friendship.

But listen!

Perhaps you can hear it too?

Perhaps if we listen carefully enough and open up our hearts, we too can hear and repeat ourselves the words of another musician who has now passed on ---- a guitarist who on a hot August afternoon sang and strummed that one lyric that alone can keep anyone from being a motherless child ---

**FREEDOM!**
Bibliography


Response to the Plenary Keynote Address

“Local, National and Global Implications of the USPHS Syphilis Study” by Ndunge Kiiti, PhD, Associate Professor, Houghton College

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Author Note

This article summarizes the author’s panel response to the ethics and health care keynote lecture of Dr. Ndunge Kiiti on April 3, 2013 as part of the Public Health Intensive Ethics Course at the National Center for Bioethics in Research and Health Care at Tuskegee University. The opinions in this article are those of the author and do not represent the views of the agencies the author serves.

Keywords: bioethics, vulnerable populations, health disparities research, global issues

Summary

Dr. Kiiti has offered us a full and rich plate of ideas and concepts in her paper “Local, National and Global Implications of the USPHS Syphilis Study at Tuskegee, especially for Women”. She opens with the powerful observation that the infamous “…Syphilis Study [at Tuskegee] is a critical part of world history…[which]…has implications across the world”, and she then quickly poses the central line of inquiry for her paper, namely: “How does this study influence the way we navigate our work among vulnerable populations…?”.

I would like to stop right there for a moment…and examine a bit more closely this issue of ‘vulnerable’ populations which she so acutely targets as central to her goal. Who, exactly, are the ‘vulnerables’?

Late in our series of published papers from our Tuskegee Legacy Project, which was funded for a decade by NIH from 1999 through 2008, we undertook the analysis of some data we had collected in our second major field study, the 2003 3-City TLP Study, that addressed this issue of who is it exactly that the public says comprises the ‘vulnerables in biomedical research’ (Chiu & Katz). The very fact that we ourselves put off analyzing this issue of who the public identifies as ‘the vulnerables’ in biomedical research until we had published 13 other articles clearly reflects that it was not one of our initial central research questions. Nevertheless it proved to be a research question of greater historical importance.
than we had ever imagined. For in conducting our literature search of some 3,605 published articles to write the introduction section of our paper on ‘vulnerables’, we—most unexpectedly, I can assure you—unearthed the astonishing fact that we apparently were the very first research group at large to study and publish an answer to the seemingly fundamental question of “Whom does the public at-large define as ‘the vulnerables’ in biomedical research?”

The voice of prominent research organizations, (such as NIH and major foundations such as the Pew Foundation and the Kellogg Foundation) as to who comprised ‘the vulnerables’ had been clearly articulated for decades via the published research they had sponsored as they, for example, officially had designated children, prisoners, pregnant women, mentally defective persons, or economically or educationally disadvantaged persons as vulnerables (Chui & Katz). For these national-level research organizations had a history of defining ‘the vulnerables’ via their periodic announcement called Requests for Applications (RFAs) or Requests for Proposals (RFPs). They had their say in those targeted to-be-funded projects as they ‘spoke their peace’ as to who comprised ‘the vulnerables.’ Similarly, the academic research community at-large across the country also had their say as to who comprised ‘the vulnerables’ via their submitted grant ideas and proposals using an array of NIH grant mechanisms, e.g., the R-series of grant awards, the P-series of grant awards, and more recently the U54 center grant awards. Clearly two national constituencies, the national-level research organizations that fund research and the purveyors of research (i.e., the community of academic researchers) had expressed their voices on who constitutes ‘the vulnerables.’

Interestingly enough, it turned out that in our literature search through all those 3,605 articles under the search term ‘vulnerable populations’, over 99.8% merely named ‘the vulnerables’ they had chosen to study and presented their findings, with only 6 articles having even attempted any definition of the vulnerables in their study….and only then from their own perspective as health researcher or public health practitioner. Not one article of those 3,605 had ever addressed the question of who ‘the public at-large’ thought constituted ‘the vulnerables’ in biomedical research. And the answers we obtained from our random-digit dial telephone survey of over 1,100 adults in three U.S. cities on what ‘the vulnerables’ were—indeed—most interesting, if not absolutely intriguing.

Our initial analyses revealed significant differences as to who was named as being ‘the vulnerables’ in biomedical research between African-American subjects and White subjects…..with Puerto Rican subjects expressing an opinion that was ‘in-the-middle.’ Then a more detailed analysis which separated Puerto Rican subjects into those living in San Juan, Puerto Rico and those living in New York City revealed a deep split between those two subsets of Hispanics. African-Americans and New York City Puerto Rican Hispanics each named themselves most frequently as ‘the vulnerables’ in biomedical research with Whites most frequently naming the elderly as constituting the ‘vulnerables’ (and only listed race/ethnicity as a distant 4th on their list of vulnerables). Overall, San Juan Puerto Rican patterns of answers mimicked the response pattern of Whites, while NYC Puerto Ricans answer patterns mimicked the response patterns of African-Americans, thus comprising a clear indication of ‘self-perceived’ class distinctions, i.e., who belonged to the ‘group in power.’

Clearly, we have a ‘message’ in this set of responses portraying the vox populis statement of who comprises ‘the vulnerables’ in biomedical research. This message reminds us of ‘how very local’ this definition will be globally, despite national-level summations by national-level organizations which tend to simplify the issue on the national level so as to achieve a political consensus to allow movement forward. But, as the vox populis so clearly articulated in our 2003 TLP study suggests, there are ‘local factors’ that must be taken into account, factors reflecting specific cultural realities with careful attention to an insightful and knowledgeable ‘read’ so as to eliminate our species-regrettable tendency for each ‘sub-group’ to act in self-interest. This ‘self-interest’ factor was perhaps best—and most pithily—stated by the cartoonist and social satirist Walt Kelly, the creator of the Pogo comic strip, in his 1972 daily newspaper strip when he put these prognostic words into the mouth of his lead character, Pogo (a possum living in the Okefenokee Swamp): “We have met the enemy, and he is us!” Hence, while inclusion of the vox populis is needed, it will need to be interpreted with local knowledge and insight.

To return to Dr. Kiiti’s posed question so central to her line of inquiry, namely: “How does…[the USPHS Syphilis Study at Tuskegee]…fluence the way we navigate our work among vulnerable populations?”, we can see that ‘some work has yet to be done’ even to determine who it is, exactly, that comprises ‘the vulnerables’. Moreover, advances in our knowledge will require moving this topic from ‘broad concepts’ (which are fine for conceptual discussions, e.g., the poor, the uneducated) to detailed operational naming of specific sub-populations within specific countries if we take on this task on a global scale (e.g., who are ‘the poor’ or ‘the uneducated’ in this region of this country, much less than just ‘in this country’). It all is then complicated by ‘who is doing the defining.’ Will it be politicians, or non-elected public health officials, or will it be, truly, the vox populis, i.e., the voice of the people themselves? And, if ‘by the people’, will it be defined by ‘those who see themselves as being in power’ or ‘by the powerless themselves’, i.e., a class battle? Then think globally, where even implementing ‘acts for the public good’ in a democracy is complex, convoluted and oft-stalemated, …then picture it as it might ‘work out’ in a dictatorship where ‘speed of decision-making’ is the only virtue. Having raised that complex specter to contemplate, let me compliment Dr. Kiiti for courageously opening the door to this seemingly overwhelming complex task to tackle…and now rapidly shift to a second issue she raises.

Moving beyond the complexity involved in the mere defining of ‘the vulnerables’ on a global scale, putting either research studies or resultant specific programs for the vulnerables into play globally is fraught with dangers for those very vulnerables. After all, the first dictum of clinical care universally is ‘First, do no harm’. Hence, how could a research project designed to help the ‘vulnerables’, or resultant programs targeted at the needs of those ‘vulnerables’, result in adding to their already existing, and burdensome, woes? Let me begin with my experience in the state of Connecticut, a most civilized, structured and organized place.

We were in the field data collection stages of a four year clinical trial we were conducting in 110 towns and cities across two states to test the effectiveness of a newly formulated toothpaste to prevent dental decay in school children. A simple, harmless toothpaste study in one of the ‘most civilized, organized’ places to live on the globe! What ‘First, do no harm’ concerns could we possibly have encountered in that environment?
Interestingly on annual repeat examinations, we discovered that one young 12 year-old girl not only showed signs of dental neglect upon the initial baseline examination (in the midst of all of Connecticut's wealth and dental services), but that our initial admonition to the school authorities (nurse and principal) to 'speak to the parents' about this observed suspected child neglect, did not show any resolution at the next annual dental exam. The parent was simply ignoring rampant, untreated, advanced dental cavities throughout this child's mouth. A second conversation with the school authorities revealed their concerns (fears, literally) of speaking to the sole parent, the father, who was considered to be a 'known bad guy' and they feared retaliation, both to the child and to them if they told him. And all this in the lovely, and well-off and well-guarded, state of Connecticut! Hence, as we bring research activities into the global corners of the earth for the good of communities, we must be acutely aware of our concomitant responsibility for the protection of each individual participant within their local circumstance and culture. What harm might be brought—inaudiently—to the wife of an irate husband within any number of cultures that are totally male-dominated as to family decision-making, as we simply invite that wife to participate into a study using our typical informed consent form? A caution to keep in the forefront of our mind.

Finally, let me address another very important and key concept that Dr. Kiiti raised in her paper: the role of communication. Dr. Kiiti very properly identifies it as a key concept in the unfolding of the story of the USPHS Syphilis Study at Tuskegee. She laments the many years dominated by the 'culture of silence' for the 40 year period from 1932-72, and properly suggests that taking this issue successfully into the future on a global scale will require a "dialogical process approach" for effective communication. She further appropriately points out that either "...the lack of information or access to the wrong or dishonest information...can be harmful" and that "[n]on-disruptive and sustainable change must come through a society's communication system." Finally, she advocates for "participatory development communication" which she states is "a two-way, dynamic interaction", one that "transforms 'grass-roots' people...leading to self-reliance." Dr. Kiiti concludes with a warning that only by utilizing this type of communication will people render themselves "not vulnerable to outside voices or agendas" and she strongly suggests the use of "diverse modes of communication" allowing people to advocate for themselves.

Yet I, for one, fear that within the reality of this modern world, indeed a reality at the very heart of today's communication world, may lie a tool that will impact, and likely impede, Dr. Kiiti's hopeful vision. I fear 'the blog....and its perpetrator, the bloggist.' For in today's 'instant communication mode', and in today's 'everyone has a voice to be heard and valued' belief system, not all 'everyone's' are equal in either knowledge, or goodwill, or even intent. Self-proclaimed experts 'professing to have your best interests at heart' abound—as ever, and worse today as they have bountiful access to thousands if not millions via the internet, blogs, texting and tweeting. And given the world's access via affordable cellphones to these lines of misinformation, if not outright malfeasance, keeping that desirable 'participatory development communication' honest, forthright and factually correct will prove a huge challenge globally.

Reference

When Race Matters: Race, Gender and the Cultures of Health and Medicine
By Karla Holloway
A Response

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Author Note
This article summarizes a response to the keynote address given by Karla Holloway at the 2013 Public Health Ethics Intensive course on April 3, 2013. The course was sponsored by the National Center for Bioethics in Research and Health Care at Tuskegee University. The opinions expressed in this manuscript are those of the author and do not represent the official position of the institutions the author serves.

Abstract
Both in her book and in her address, Duke Professor Karla Holloway called her readers and listeners to a new awareness of a particular aspect of our lived reality. She examined the ways in which our culture encourages us to accept passively the business-as-usual approach to the treatment of the vulnerable bodies of women and people of color. Holloway energetically defended the right of privacy most often granted to middle class, white heterosexual men even as she calls for a global exercise of this right to be enjoyed by women and people of color. In identifying the discrepancy between the groups who benefit from this innate human right and those who do not, Holloway names a cultural disparity that has no right to exist. She furthermore notes that the denial of the right to privacy for women and people of color has occurred without the consent of those so denied. Tragically and historically, their claiming of the right to privacy has been costly. Women, people of color, and other minorities become public spectacles, and endure torture, abuse, and other inequities when they attempt to assert their basic human rights. This needs to change. The first step is awareness of the problem.

Keywords: privacy, vulnerable bodies, culture, identity, race, gender, consent, spectacle, contagion

Introduction
On April 3, 2013, Karla Holloway, PhD, James B. Duke Professor of English and Professor of Law at Duke University, delivered what she described as a ‘postscript’ to her book entitled Private Bodies, Public Texts: Race, Gender, and a Cultural Bioethics (Duke University Press, 2011) at Tuskegee University as part of the Public Health Ethics Intensive course sponsored by the National Center for Bioethics in Research and Health Care located on the university campus. As a professor of cultural studies, Holloway observes the subtexts of our lives. She sought to become aware of that which affects our identities, especially race and gender, without our knowledge and consent. Indeed, Holloway examined aspects of life that escape our notice because we are unaware of their presence and impact. Holloway attempted to turn the lights on for us. She sought to enable us to see the world in which we live for what it is, and she urged us to restructure significant elements of it in the name of justice and equality for all. My remarks here pertain primarily to Holloway’s presentation at Tuskegee and only tangentially to her book.

Holloway’s Argument
Holloway argued that the bodies of women and people of color have been and continue to be used for profit and other kinds of personal gain by those who feel no compunction either to compensate or even notice those whom they exploit. She illustrated this claim in many ways, including examples in literature (e.g., The Help by Kathryn Stockett), medicine (both the life of Henrietta Lacks and the book about her by Rebecca Skloot as well as the death of Terri Schiavo and the media circus that led to the passage of “Terri’s Law”), the media (radio talk show host Bill Bennett’s remarks about how to reduce crime in this country, i.e., “abortion every black baby in this country” [September 29, 2005] as well as the media’s continual shaming of single parents), and, of course, the USPHS Syphilis Study performed on the men of Tuskegee. In each case, Holloway critiqued both actions taken and attendant attitudes surrounding the events. She forcefully decried the attitudes and atmosphere that have permitted and even encouraged the conditions that require such legal solutions as civil rights, women’s rights, and marriage equality legislation because of what those laws have cost the individuals whose bodies were on the line that led to these laws. In short, while the passage of some laws has led to greater equality, the path toward their passage has been strewn with vulnerable bodies who have been denied their sanctuary of privacy. The public spectacle that these bodies were forced to become is too costly a price for justice. We can and must do better as a society to respect and claim the right of privacy for everyone.

My Response
Holloway’s brilliant, incisive, and timely critique of the cost of progress came to an audience well equipped to appreciate the truth of her insights. Each point she made touched first one nerve and then another as family members of the victims of Tuskegee’s compelling and problematic past and others listened with rapt attention to this validation of their history and experience. Each person could listen with their own experience playing in the background of their mind as the speaker clarified some of the blurred impressions of their memories. Holloway’s slides and commentary resonated with those from whose vulnerable bodies a terrible price for social progress had been extracted. This speaker, author,
and professor reached into her own extraordinary past to present a future full of hope and possibility if only we would celebrate the R-E-S-P-E-C-T so boldly proclaimed in song by Detroit’s own Aretha Franklin.

Applicability of Thesis

A careful study of Holloway’s words reveals a depth of nuance that can enhance anyone’s perspective on areas of race and gender as well as the other disparities in our society. Much of what she said could be applied to the aged, the physically and mentally challenged, and all those who are in any way living in a vulnerable body. At the outset, however, Holloway clearly stated her interest in race and gender in particular. This is because the visibility of women and persons of color too often marks them as exceptions to the norm.

Perhaps some might argue that every person, at some moment in their lives, has been treated as a vulnerable body. Even the able-bodied, middle class, white, heterosexual males, who appear to be invulnerable to the gaze of the strong, may from time to time experience the devastating feelings of powerlessness and being used for another’s gain. What separates white heterosexual males from women and people of color, however, is that the former never or almost never experience a disruption from this state of vulnerability. Women, people of color, the congenitally disabled and gay individuals may not leave their situation, while the white males described by Holloway experience their disruption as non-normative, out of the ordinary, and certainly not the way nature intended. The confusion that results in the minds of women, people of color, and the others is precisely because they are other. They are, at best, second in the order or creation, and this, they are often told, is God’s will for them. Hence, while we all experience the shame and vulnerability that Holloway describes from time to time, the point of her remarks is that women and people of color, in particular, know not what it is to be normal. They are always contrary to the norm; theirs is an intrinsic vulnerability.

The Right to Privacy

Holloway very convincingly presented her conviction that the right to privacy is a basic human right. Unfortunately, she noted, only white heterosexual males have that right. “Othered” individuals—all those who are not white heterosexual males—are not granted that right and, therefore, are exploited both in private and in public life. In fact, the bodies of these othered individuals sometimes become the means toward an end: legislation that seeks, in the best of times, to dismantle the myths that have supported the otherness in the first place. Often, however, these ends are not touted as worthy goals, and the exploitation continues unabated.

The media magnify the vulnerability of the bodies in question and deny them their right to privacy by calling all to feast and revel in their discomfort. What is worse, the media exploit whatever privacy these bodies may have had by putting every intimate detail possible on public display. Their bodies lose their privacy during endless discussions, as they are forced to share every intimate detail with the public for public consumption. Their bodies lose their privacy during endless discussions, as they are forced to share every intimate detail with the public for public consumption. Their bodies lose their privacy during endless discussions, as they are forced to share every intimate detail with the public. Their bodies lose their privacy during endless discussions, as they are forced to share every intimate detail with the public. Their bodies lose their privacy during endless discussions, as they are forced to share every intimate detail with the public.

Details of the principals and their families. Holloway cited one convincing illustration after another to prove her point. From Henrietta Lacks and The Help, Holloway argued that the focus of the media on this kind of particularity hinders an adequate rendering of the stories of the oppressed vulnerable bodies. For example, hundreds of children die in major cities across the land, and we only grieve nationally if a particular child has a name and a story that can be marketed across the land. The hundreds of nameless children who die do not have “grievable deaths,” and, therefore, are ignored.

Holloway’s concern with the normativity of some bodies and the vulnerability of others is crucial because the consequences of this injustice reach into nearly every facet of human existence. Their effects rob individuals of much of their pride and dignity. This results in a separation between heterosexual white men and others, and this separation in turn results in a fear of contagion by the normed, e.g., They may not sit next to us in school. The othered, it seems, carry the possibility of contaminating the normed through close proximity. Even the mere hint of contamination requires the privileged to view the vulnerable with suspicion and fear. While at once fascinating and feared, the other must be controlled and, therefore, denied their human right to privacy.

Stories of the fascinating and feared other, then, become the property of those who wish to consume them.

Those who wish to lessen the consequences of changing their intrinsic vulnerability must be willing to expose themselves to public scrutiny and lose their privacy in the process. It follows that those whose lives are touched by what should be viewed as private issues, e.g., contraception, abortion, HIV/AIDS, single parents, and gay marriage, are offered up for public consumption. Their bodies lose their privacy during endless discussions, as they become public spectacles. In short, Holloway stated: “It’s nobody’s business who I live with, whether or not I’m married to my spouse or partner, how many children I’ve had, whether or not I’ve had an abortion, and yet to make these things become rights that are normative, somebody has to tell.”

Conclusion

Karla Holloway offered a vital and timely contribution to the question of why the bodies of women and people of color continue to be used in a public way. Her keen sense of justice challenged her listeners to look around them and examine their culture in a new light. She helped her audience to name their experience and claim their identity. In sum, she called us to “wonder at the consistency of certain gendered and racialized narratives and to acknowledge the inconsistency of others.” If privacy is a human right, then why are only some persons allowed to exercise it, and when and how will this reality change?
Finally, Holloway charged “black bodies to learn that first level of citizenship, the level where respect happens, where privacy is a right for everybody. And if and when we become spectacles, we wrest the images back the bodies, the families, to our own truth telling, to instruct ourselves on the policies of ethics without having to reinvent them for the public square, to claim our own standpoint as a legitimate site for future work.” Holloway did not follow up her observation with a set of solutions to what she sees as a serious problem; instead, she left us to wonder about the world in which we live. Her goal, seemingly, was to call our attention to the fact that certain bodies are available for public scrutiny and commercialization and, during that process, their privacy is eradicated.

Holloway’s work deserves to be read and heard. Tuskegee University did us all a favor by bringing her to campus and allowing her to promote the scholarship she has so diligently wrought.

Abstract

The misuse of private bodies and imagery for public consumption has direct implications into the racial fabric of the United States (U.S.). Faith plays a major role in the health and healthcare decision-making and ultimately relegates to mistrust. Since federal health record keeping began, regardless of other demographic factors, Black people continue to record statistical significant disparities. U.S. health disparities are documented by race/ethnic, socioeconomic, gender, and geographic demographics. At the heart of American law, politics, economics, religion, and morality has been the question, implicitly or explicitly, of Black people’s bodily color and worth; and therefore, blackness has been equated to sin and sin being that of blackness; which poses a ethical problematic into the justification and rationale of the mistreatment of Black private bodies becoming public texts. Not until the relationships that created this misrepresentation and treatment of a people are explored and restored can the ultimate concern for health and wholeness begin. Theological discipline informs that it is through the retelling of stories/narrative and lived experiences that communities are able to bring healing to the brokenness and the reliving process can begin through adopting renewed habits that bring about better possibilities.

Keywords: faith, healthcare, ethics, disparities, theology
First and foremost, it is truly an honor to be here and an extreme honor that the committee provided me with such an opportunity on this day to be a respondent. The journey of life lends us all a narrative. In my narrative, it is truly amazing each time that I come to Tuskegee, to know this is the ground where my mother stood many years ago as a young woman participating in the practical skill development training here at Tuskegee many years ago. These skills afforded her the opportunity to obtain a position in the garment district in Cleveland, Ohio once she migrated from Decatur, Alabama in the 1950s. Subsequently, the skills allowed her to not only raise her own children, but grandchildren as well and I am honored to be a benefactor of such hard work and sacrifice—it will always be appreciated and remembered.

I often have traveled to Tuskegee regularly for several years as a Visiting Scholar of the Bioethics Center; thus, I am very familiar with the humbling, uncomfortable and perplexing narratives that have brought us here today. I reflect on the imagery of the physical, psychological, and social harms inflicted by the United States Public Health Service in their Syphilis Study conducted at Tuskegee (Warren 2006, 78-96). I also reflect on why we as Black men and women have every right not to trust the healthcare industry which has systematically oppressed and abused primarily Black men and women (Institute of Medicine 2003, 143-144) for the salvation and well-being of others.

In response to Dr. Holloway’s profound presentation “When Race Matters: Race, Gender, and the Cultures of Health & Medicine,” I contribute the following.

My day to day role is the Chief Financial and Operating Officer (CFOO) of the HEALing Community Center, which provides primary and specialty healthcare service to persons who are uninsured and underserved. I am faced daily with adherence to patient confidentiality, quality of care, quality assurance, quality improvement, establishing and approving health care policies that include locations and hours of services, scope and availability of services and quality of care audit procedures. I am also faced with establishing and approving financial management practices, establishing and approving personnel policies, measuring and evaluating the organization’s progress in meeting annual and long-term programmatic, clinical and financial goals. In addition, I am faced with developing plans for the long range viability of the organization by engaging in operational and strategic planning, ongoing review of the organization’s mission and bylaws, evaluating patient satisfaction and service utilization and monitoring organizational assets and performance; and assuring compliance with applicable federal, state and local laws, regulations and policies.

Further, I am confronted with family members being irritated that they cannot have access to family members’ records or be privy to the provider-patient discourse regarding their loved ones; all in which are very sensitive considering they are only seeking to ensure access to family members’ records or be privy to the provider-patient discourse regarding and assuring compliance with applicable federal, state and local laws, regulations and policies.

Our organization values and respects the quality and care of life, and we seek to adhere to Health Insurance Portability and Accountability Act (HIPAA) compliance and ensure that all hard copy charted records are stored securely in the medical records file storage room. However, the advancement in technological innovation now allows records to be primarily stored in the electronic health record (EHR) system and secured through practice management procedures.

Patient records are not shared without written permission/consent. Information about patients is not discussed outside of our organization or in the halls where other patients may hear and if so the result is termination, as I am zero tolerant with an A-type personality. However, based upon the building composition and the era in which it was built, this becomes a challenge as walls are thin and ventilation systems become pathways to hearing other patients’ confidential information.

There once was a time when records were paper-charted. Then time progressed and we had facility-based servers that housed the electronic data onsite. Now we are in the era of cloud-based systems that are stored in cyber space at offsite locations where nobody knows exactly the secure protocols. Also, if you seek to use another EHR database, there are complications in conversion as no system is alike and you also risk the old patient data still dangling in the cloud. Patients have the right to their health information and can have remote access to the EHR system and nobody can monitor the breach of their personal email accounts and access codes.

My response is not one of advocacy for health care administration negligence or lack of compliance nor do I endorse the business of the health care industry with its sole focus being profit rather than patient-centered care; I seek to be one who provides context to the day-to-day operational challenges that healthcare organizations face in establishing and protecting trusted relationships with persons who look like you and me, and who share the collective experiences of distrust. The mission of our organization is to improve individual, group, and community health and well-being for populations that are at risk and underserved by:

1. Providing comprehensive health care
   (medical, oral, mental health, and health education) services;
2. Eliminating disparities in health and health care delivery; and
3. Enhancing and building community relationships

Further, we strive daily not to breach patient confidentiality by any means, but to be reparers of such breaches of trust and confidence in health care delivery.

Dr. Holloway, your articulation of “Private Bodies, Public Texts” forces me to consider the variables of society, law, and medicine in terms of what makes a narrative and how the stories about medicine actually becomes stories about race, class, and gender. In my contribution to the discussion, the ethical dilemma is that such narratives even exist for us to discuss. It forces me as a Health Care Administrator to reflect on how to ensure private bodies remain private and are not used for public consumption, capital gain, and human subjects research. I find myself constantly reviewing claim errors, lab diagnostics, and other reports containing patient data, to ensure unnecessary invasive procedures are not being conducted. It is a constant balancing act as providers seek to address/reduce patient health complications and simultaneously reduce provider and facility liability.
The reality is that private bodies are also public texts in the form of patient charting and insurance claim submittals that are often rejected for frivolous reasons. Accordingly, providers are placed in ethical dilemmas of whether or not to overlook treatment merely because of the impact on the organization’s claim submittal rate. This scenario impacts revenue; but more importantly, it impacts the provision of quality healthcare.

Another ethical concern that you raise, Dr. Holloway, is in how some bodies are rendered up for public consumption and others are allowed their privacies (Holloway, 2013) (and I would add liberties). It is in these narratives that all are forced to reckon with the lived experiences of their deceased loved ones being experiments for scientific public consumption for the advancement of others. Despite the unprecedented explosion in scientific knowledge and the phenomenal capacity of medicine to diagnose, treat, and cure disease, Blacks, Hispanics, Native Americans, and those of Asian/Pacific Islander heritage have not benefited fully or equitably from the fruits of science or from those systems responsible for translating and using health sciences technology (DHHS, 1985). To live daily with the reality that most of the advances were outcomes of the suffering of Black life presents a daily struggle because we know that such narratives still exist. However, my response and social critique is that such narratives are the result of structural sin.

Structural sin refers to the systematic barriers that prevent health and wellbeing for specific groups of people (racial and ethnic minority populations, low income populations, etc.). In this instance, structural sin is exemplified by institutional racism, sexual bigotry and the exploitation of low-income people (Maclin, Warren, Alema-Mensah, Scriven, & Murphy, 2012). The continuous incidence and prevalence of indigence and health disparities among the Black population is associated with being underserved, under-educated, unemployed, and experiencing racial, ethnic and gender biases (Maclin et al., 2012). These historic challenges have resulted in lost faith in federal, state, and local governmental systems.

In many instances, the only perceived refuge in Black culture/community is within our tenets of faith that holds the belief that G-d’s is on the side of the oppressed; G-d will always vindicate on the behalf of those who are oppressed; and that trust can always be placed in such a G-d. The continuing experiences of racism, gender discrimination, and sociopolitical exploitation (classism) have often been countered by an African-American moral discourse resonant with themes such as the equality of all persons made in the Imago Dei (image of G-d).

Dr. Holloway, your point regarding the "Immortal Life" is more of a theological concern rather than a legal one for me that can ultimately lead to a faith seeking a greater understanding in context of exploring what it means to be a mortal being when created in the Image of G-d. It requires the legal minds, policy makers, practitioners, and insurance claim submittals that are often rejected for frivolous reasons. Accordingly, providers are placed in ethical dilemmas of whether or not to overlook treatment merely because of the impact on the organization’s claim submittal rate. This scenario impacts revenue; but more importantly, it impacts the provision of quality healthcare.

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Dr. Holloway, your point regarding the “Immortal Life” is more of a theological concern rather than a legal one for me that can ultimately lead to a faith seeking a greater understanding in context of exploring what it means to be a mortal being when created in the Image of G-d. It requires the legal minds, policy makers, practitioners, and biological scientists to wrestle with their standards and practices of care that are driven through a theological position of life, death and the necessity to embrace the imagery of blackness as being G-d-ly.

At the heart of American law, politics, economics, religion, and morality has been the question, implicitly or explicitly, of Black people’s bodily color and worth; and therefore, blackness has been equated to sin and sin being that of blackness (Earl, 2004). Therefore this results in the imagery of Black bodies being rendered up for public consumption in biomedical research, media exploitation, unequal treatment in healthcare delivery while others are allowed there privacies and liberties of quality treatment and care. The “challenge must be seen as Blacks’ response to whites’ categorical claim of the sinfulness of the African’s blackness of body and soul” (Earl, 2004); and the re-creation of themselves without embracing Black suffrage as being inevitable. For if one views suffering as being inevitable and mortality as the outcome, the human being then becomes a subject of death and an object of experimental exploration with no regards for the sacredness of life; as if the Spirit no longer lives in the case of Mother Henrietta Lacks.

Dr. Holloway, the “Immortal Life” made me wrestle with Black cultural norms and our experiential vulnerabilities to G-d and others, albeit our religious, spiritual and/or philosophical understandings of life. It forced me to raise the empowering question of why, for G-d to answer to humanity of why, rather than humanity answering to G-d. So humanity (that is created in the Image of G-d) finds itself in the context of being Black and experiencing horrific actions of others that are contrary to a G-d that is viewed as being just; yet injustices continue to exist in the earth to those of us who have been labeled as being the least of these. Therefore, it forces us to question why Black life is often viewed as the least.

In the biblical narratives of oppression and injustice, we can read the undergird in the text suggesting that G-d is on the side of the oppressed; but yet oppression has a permissive will to exist and to be experienced and endured by an omnipresent deity overlooking with no divine intervention. I continue to raise the empowering question to G-d and to all of us, “Why is it that we as Black people and people of color are always the oppressed in G-d’s plot?” And why in this plot for civilization to become a heaven on earth for others is done at the demise of us a people in the right here and now in the quest for others individual and group “Immortality” and whiter than snow imagery of perfections?

The study of professional ethics has informed us as it seeks out values and standards that the value of life, particularly Black life, is often disregarded as being of little value. History recorded and gave us insight that Planters (transporters of slaves) valued neither the health nor the life of enslaved Africans because Africa only provided a replenishment of bodies for free labor (Berry & Blasingame, 1982). Thomas Jefferson (author of the Declaration of Independence and one of the architects of the Constitution of the United States, and also a legal mind) declared that there were real distinctions that nature had made between Africans and whites. He identified these real distinctions as inferior African intellects, ugly and odoriferous bodies (yielding an odor/morally offensive), and a deficiency of tender feeling (Jones, 2007). There is a systematic structure of oppression, which even the architects of the governmental system perpetuated in ideology, that suffering is nature’s design. James Madison, who is rightly called the father of the Constitution, believed it a natural law that disparities in human talents will produce an “unequal distribution of property” (Hacker, 1997, pg. 34). This fundamentally serves as an understanding into the Eurocentric interpretation of human life and its value. Eurocentric understandings of life are centered in the thoughts of James Madison, who purports that the nation would always be divided into “those who hold and those who are without property” (Hacker, 1997).

Dr. Holloway's point regarding the law of the body is deeply rooted in theological and religious fabric. These United States have a lack of value, standards, or regard about the sacred temple of Black bodies and the view of Black life being public property. The result
has been unequal treatment and “health disparities”. Health disparities are defined as gaps in the quality of health and health care across racial, ethnic, socioeconomic, genders, and geographic locations. These disparities have resulted in Blacks excessively dying more that their non-Hispanic White counterparts and continuing to rise despite advancements in technology. Currently, 80% of the seven leading causes of excess deaths for Black people are: cancer, cardiovascular disease and stroke, chemical dependency (measured by deaths due to cirrhosis of the liver), diabetes, homicide and accidents (unintentional injuries), infant mortality, and HIV/AIDS (U.S. Department of Health and Human Services, 1985; U.S. Department of Health and Human Services, 1990). It is our Black image that serves as the poster for these leading causes.

Despite the efforts from health science and biomedical research to improve overall health status of the U.S. population, racial and ethnic health status disparities remain. Public policies and programs to eliminate health disparities are elusive. The programs are not supported with sufficient monetary and human capital to reach intended objectives. While 2010’s federal health care reform legislation included a number of components designed to greatly expand access to care for the uninsured and underserved, it is unclear at this time whether or not these measures will actually benefit states like Georgia and Alabama. Alabama and Georgia are two of the 26 states that filed suit asking that the Patient Protection and Affordable Care Act be struck down.

Measurable disparities also exist in the areas of education, employment, and psychological wellbeing with regards to health. All of these disparities can be attributed, in part, to the historic and current adverse effects of slavery, Jim Crow, and segregation in the United States (Fluker, 1998). Until these challenges have been fully addressed by federal laws, regulations, policies, and programs, attempts to ameliorate the root causes of health disparities will continue to have little effect.

Dr. Holloway, your contemporary statement that I consider to be words of wisdom for us is as follows: Living must do due diligence to memories of culture, with careful considered attention to the ethics of our conduct-whose bodies finally matter, whose privacies we protect” (Holloway, 2013). Because society places individuals at risk for disease, dysfunction, disability, and premature death, health protection is imperative (Warren, 2007). These actions and practices call all to a level of protective accountability and respectability with a responsibility to seek justice to eradicate the suffering and no longer promote the imagery of inevitable suffering among Black people.

In closing, the ability to remember, retell, and relive are components of integrity formation. In failing to remember the constructs that formed the habits that cause a person or community to adrift is problematic in the cultivation of character. We cannot critically examine the moral, ethical or legal discourse and practices in our collective experience without taking seriously the long and arduous history of domination, slavery, Jim and Jane Crow, segregation, and its consequences on the psychosocial health of all persons living in the U.S. (Fluker, 1998). The aforementioned is the byproduct of what has continually allowed the imagery of Black life to be portrayed in a negative context. (Fluker, 2009)

The misuse of Black imagery and the present health conditions of Black people are not acts of nature, but are defined through historically and socially specific human interaction in society (King, 2002). Not until the relationships that created this misrepresentation and treatment of a people are explored and restored can the ultimate concern for health and wholeness begin. These relationships are actually interrelated at the point between faith and health. Faith and health interact at the point of relationships (Warren, Lockett, & Zulfiqar, 2002). An ultimate concern cannot be identified unless there is a relationship. When relationships are repaired, then and only then can one move to being a whole and healthy person, having a faith that is vibrant, intact and connected (Warren, et al., 2002). We and are forced to remember, retell and relive these experiences that has shaped public misrepresentation of Black life and the misuse of our private imagery for public negative consumption. My theological discipline informs me that it is through the retelling of stories/narrative and lived experiences that communities are able to bring healing to the brokenness and the reliving process can begin through adopting renewed habits that bring about better possibilities.

Thank You!

• Editor’s Note: For those readers who may not be aware, the spelling of the deity as G-d in the above text is an intentional academic usage.


Plenary Responses

The Context of the Affordable Care Act: Demographics, Devolution, Community Benefit
A Commentary Response to the Context of the Affordable Care Act Plenary Address of Bailus Walker, Jr., PhD, MPH

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Abstract

This article is based upon the response to the Plenary Keynote Address, Context of the Affordable Care Act, presented by Bailus Walker, Jr., PhD, MPH during the April 2013 Public Health Ethics Intensive Course at Tuskegee University National Center for Bioethics in Research and Health Care. The opinions expressed are those of the authors. With gratitude, I acknowledge the support provided by the Dr. Cecilia L. Dows Scholarship Fund of the American College of Dentists while in pursuit of the Master of Arts degree in Bioethics and Health Policy from Loyola University (2012).

Keywords: Affordable Care Act, devolution, community benefit

Introduction

Dr. Walker is to be commended for his detailed explanation of undergirding principles as well as preliminary outcomes of the Patient Protection and Affordable Care Act (ACA). It is notable that his knowledge about the concepts is experiential and iterative because of his population health management work in the state of Massachusetts.

The primary intent of this response is to synoptically review contemporary societal factors that influence common morality and parochial praxis associated with the ethical provision of essential health benefits. Specifically, initial outcomes of the Patient Protection and Affordable Care Act, America's demographic trends, conceptual approaches to devolution, common good-community benefit transition, community benefit concepts and the state of mind of the patient/consumer when immersed in the "healthcare marketplace".

It is the secondary intent of this response to empower each conference participant, by providing information, examples, and a rudimentary toolkit for both participating in parochial devolution discussions- whether on IRBs, hospital ethics committees or in political action- as well as to receive health care as an informed autonomous partner in personal and community wellness.

The Patient Protection and Affordable Care Act

Providing insurance coverage and access to high-quality care for all Americans is an important principle in combating health disparities. According to Pam Belluck, "for the first time in two centuries, the current generation of children in America may have shorter life expectancies than their parents, according to a new report which contends that the rapid rise in childhood obesity, if left unchecked, could shorten life spans by as much as five years." (Belluck, 2005) Further, "uninsured adults and children are less likely to have a regular source of primary care and less likely to receive effective health services." (Williams, 2007) This reality is even worse for low income minority families because "private insurance is either unavailable to low-wage workers or premiums are prohibitively expensive." (Williams, 2007) Therefore, it is crucial that these inequities are addressed and health insurance programs be offered as a component in a coordinated effort to reduce health disparities. Recognizing the gravity of the situation, the Obama Administration and the 111th Congress passed the Patient Protection and Affordable Care Act, referred to herein as the Affordable Care Act or (ACA). Although the Affordable Care Act is a revolutionary piece of federal legislation, it is actually an iteration of parochial and statewide population health initiatives designed to assure community wellness.

According to Ron Suskind, the Pulitzer Prize winning author of Confidence Men, Wall Street, Washington and the Education of a President, (Suskind, 2011) primary architects of the Affordable Care Act were physician philosopher Ezekiel Emmanuel and economist Peter Orszag, former Director of the Office of Management and Budget. Additionally, there was significant input in the deliberative process by Massachusetts Health Connector founder, Jon Kingsdale as well as representatives of employer groups, health care organizations and health insurers. Together, these subject matter experts sought to provide the infrastructure of a wellness safety net for those who are under insured, uninsured or otherwise exposed.
to unacceptable levels of risk factors threatening wellness, without infringing on personal autonomy or state’s rights.

During their presentations entitled *The Context of the Affordable Care Act and The Affordable Care Act: The Ethical Implications on Public Health*, Dr. Bailus Walker Jr. and Dr. Mary McIntyre have outlined national policies, national social contexts, Alabama’s social context then reviewed examples of interpretation and implementation of national policies. Since 2010, indicators of progressive action toward the statute’s goals have been tabulated and examples are included in Figure 1. These are positive outcomes and planned objectives.

![Figure 1: Patient Protection and Affordable Care Act Initial Outcomes](image)

**Three Forces Changing Our Nation’s Future**

Much of the discussion in the media has focused on the constitutionality of the ACA, the legislative process, and the options available to individuals and states as well as potential costs. One might consider these factors as definitive of the contextual paradigm. However, as we consider the dynamic social context within which the Affordable Care Act is being progressively implemented, it is wise to note the multifaceted evolution of our society.

A synopsis of *The Three Forces Changing Our Nation’s Future* (Kirsch, 2007) as outlined by Kirsch, Braun, Yamamoto and Sun, is represented in Figure 2.

![Figure 2: The Perfect Storm: Demographic Trends](image)

### Divergent Skill Distribution

As demands of the employment marketplace become more complex, the skill sets within the workforce should respond reflexively to engineering and environmental innovation. When compared to the workforce of previous decades, there is a measurable decline in the ability to do basic arithmetic and read at levels commensurate with age and experience among the emerging workforce. As those with the highest numeracy and literacy skills mature and retire, expressions of American ingenuity and productivity within the United States are measurably impacted.

Further, there is an increased urgency when considering 21st century skills to not only focus on fundamental mastery of core subjects but to understand and address issues of a global nature. Critical thinking, effective communication and problem solving skills are vitally important. Today’s workforce will need significant levels of environmental, business and health literacy, particularly in the context of this discussion. Far too many are unable to interpret basic health services and information or the values of the delivery systems which provide the healthcare services.

### Seismic Changes in Wealth Distribution

Even as technology has been a catalyst for innovation, communication, transportation, productivity and quality of life, it has effectively minimized geographic, political, and ideological boundaries, globalizing our employment marketplace. While manufacturing jobs provided one-third of American employment in 1950, by 2003 only 10 percent of the American workforce was involved in manufacturing. According to the
Center on Budget and Policy and Priorities, from World War II into the 1970’s the economy grew and perhaps more significant, the prosperity was broadly shared. Since that time the economic growth is slower for middle and lower income people and a greater income and wealth inequality is emerging with a concentration of income at the very top of the distribution, at levels not seen since the 1920s. For those living at the poverty level there was a sharp decline for the ten-year period ending in 1969 but there has been minimal change since that time. While there are many variables that impact wealth, growth sectors in employment are associated with college education. The lifetime earnings among college educated males can be as much as 91 percent higher than males without advanced education.

Population Growth
Between 2000 and 2015 immigration will account for fifty percent of our nation’s population growth. The growth of our labor force will be slower than during the last decades of the last century and native-born workers between the ages of 25 to 54 will account for none of this growth. Thus, our nation’s population is increasingly older and diverse. Immigration is essentially responsible for growth and we should expect cultural norms and social context to mirror such asymmetric trends.

Devolution
A simple way to understand devolution is to be reminded that as a concept, organism, or event becomes more complex, we say it evolves. Conversely, as a complex concept, organism, or event becomes less so, we might consider that as devolving. In the context of the ACA, the legislation transfers significant power from the federal to state governments giving them numerous responsibilities as well as resources to implement the coverage. In this discussion Dr. Walker examined the result of a comprehensive deliberative process to effect national policy and Dr. McIntyre discussed the state of Alabama’s praxis as it relates to population health management. As the highly evolved national policy is applied in parochial or state settings such as Massachusetts, Alabama, or local settings such as counties, municipalities or even where individuals receive health care, we might consider that devolution. While the opportunity is explicit, devolution comes with implicit risk such as accountability, actual improvements in the quality of care and the issue of state budget deficits. There are many unknowns making it difficult to completely understand the impact of devolution relative to this issue. However, historically the most vulnerable people in our society have not fared well with this fundamental policy change.

Progressive initiatives and careful monitoring of population management strategies is a niche occupied by the W K Kellogg Foundation. (Sherwood, 2010) One would benefit from visiting the Kellogg Foundation website at www.wkkf.org/devolution and from considering devolution as a watchword associated with threats to distributive justice.

Common Good to Community Benefit
For the sake of this discussion, the concept of Common Good is defined as “the advantage or benefit of all people in society or group.” (Dictionary.com, 2012) In the author’s home state of Pennsylvania, a Commonwealth, the representative body exists for the benefit of the citizens within its boundaries. The same is true within the great state of Alabama.

When health care was the domain of the individual seeking relief from disease from an individual expert in such remediation, the ethical practice of medicine was governed by principles of beneficence, non-maleficence, autonomy and justice. It can be argued that, as such relationships evolved into complex interactions between externally governed systems, not only did health care change from relational to transactional, but common good transitioned into the concept of community benefit as defined by the entities generating or taxing revenue derived from such transactions.

Figures 3 and 4 present a concise representation of the community benefit paradigm from the perspectives of the revenue taxing and health care provision. Figure 5 presents the moral and ethical undergirding principles of Ascension Health as a major health care organization. These figures illustrate concepts, here considered generally, as factors that contextualize devolution of the Affordable Care Act rather than as factors, which necessitate a detailed discussion of each and the underlying implications.
Community Benefit

Although many consider it an imperfect law, the Affordable Care Act represents the first major health-related overhaul in the United States designed to directly benefit community wellness since the establishment of Medicare and Medicaid. In fact, its explicit purpose is to provide quality affordable healthcare for all Americans. While it is likely that the aims of healthcare, “the prevention of death and disability, the relief of pain and suffering, and the restoration of functioning,” (Williams, 2007) are often not the consistent primary focus of providers and policymakers, the implementation of the ACA seeks to restore these aims as the foundation of care. Health is a special good and should be recognized as such. Access to healthcare broadens a person’s opportunities, and provides them reliable information about their health that can relieve worry and enable them to adjust to their situation. The ACA inherently makes this qualitative consideration by requiring the development and utilization of uniform explanation of coverage documents and standardized definitions. It further requires the development of a reporting system that improves health outcomes through more effective care management, activities that will prevent hospital readmission, and initiatives to improve patient safety and a reduction of medical errors. However, these steps alone are insufficient.

The ACA is built on the recognition that communities play an essential role in determining the health outcomes of the people that live there. It is clear that neighborhood issues broadly impact individuals’ daily lives. Violence, pollution, the presence of fast food restaurants and the absence of supermarkets all have a direct impact on mental and physical health, as well as indirect effects on health behaviors. Additionally, access to resources related to employment and recreation also affect health. (Williams, 2007)

While eliminating poverty and racism are unlikely to be effective approaches at a public policy level, combining healthcare interventions in conjunction with efforts that address conditions within the neighborhoods is likely to have a much more significant impact. If implemented, the Community Action Model will enhance the ACA’s benefit. The Community Action Model “is a five-step community-driven model that recognizes the need to facilitate equal skills and understanding of public health principles and strategies among all community partners and focuses on community action as a method to change policies and develop new programs.” (Williams, 2007) This model, along with utilization of community health workers and faith-based initiatives are likely to have a positive effect in reducing health disparities.

The ACA and its implications for reducing health disparities is not just a matter of community benefit, but is also an issue of social justice that imposes duties on all because they are claims based on one’s universal humanity, not on any special relationship established between identifiable parties. We, as a nation, can and should do more to establish parity in a system based on distributive justice and human thriving. The ACA acknowledges this notion as well through its prohibition of discrimination based on salary, which tends to favor higher wage employees. As the ACA will enable a diverse previously uninsured or uninsurable population to be eligible for health coverage, providers and policy makers should promote a diverse healthcare workforce, deliver patient-centered care, maintain accurate and complete race/ethnicity data to monitor disparities in care, and set measurable goals for improving quality and ensure that goals are achieved equitably for all racial, ethnic, and socioeconomic groups. Thus far, the ACA is the most significant piece of legislation that brings us closer.
to this goal. If, through the combined effort of the healthcare providers, policy makers, and communities, the ACA is fully implemented, its potential is likely to reach far beyond current estimations.

**Where Am I in This Discussion?**

Within the context of American Healthcare, the reader is part of a larger American context that inevitably and directly impacts the healthcare environment. Bias, the assignment of value based on personal preference, is pervasive in healthcare and manifests itself at all levels. This reality combined with socioeconomic factors has facilitated an environment of inequity and created a situation demanding nothing short of the ACA. So, where is the reader when engaging these various factors that create a context for such a comprehensive Act? Individually, these factors are usually involuntarily consumed when receiving emergency care in an alien culture that is made even more difficult to navigate because of the physical incapacity being treated. Additionally, you are consciously trying to absorb your current status through a lens of personal loss due to trauma or metabolic deficiency. The stages of internalizing such loss as outlined by Kubler-Ross are nonlinear, dynamic and modulated by experience, environment, culture and familial support. Starting with denial and progressing with regressive stalls through isolation, anger, bargaining, depression, acceptance, finally ending in hope.

However, at the aggregate level, the reader is located at the heart of the discussion and central to the ACA because promoting access to high-quality care for all people, including those beyond the borders of the United States is an important and necessary principle for combating inequity that extends beyond health. As Dr. Walker has aptly pointed out, this is indeed a global issue and a “failure to respond to such global [disparities] can only lead to greater poverty and deprivation, continuing conflict, escalating migration of ‘asylum seekers’ from poor to rich countries, and the spread of new and recrudescing infections, diseases and ecologic damage that will harm all nations individually and the world collectively.” (Benetar, 1998)

Where is the reader in this discussion? It is all about you and your wellness; the wellness of your family, your neighbor, your community, county, state and nation. This is the focus of the Patient Protection and Affordable Care Act.
Conclusion

The developed nations, as citizens of the world, have an obligation to address health disparities that exist worldwide. As the National Intelligence Council has demonstrated, “infectious diseases...remain the most direct health-related threats to the United States, but are not the only health indicators with strategic significance. Chronic, non-communicable diseases; neglected tropical diseases; maternal and child mortality; malnutrition; sanitation and access to clean water; and availability of basic health-care also affect the US national interest through their impacts on the economies, governments, and militaries of key countries and regions.” (National Intelligence Council, 2005) Here in the United States, the Affordable Care Act is an iteration of a progressive state law established to assure improvement in community wellness. However, the ACA aims significantly higher than the state law it is based on since its implications are far greater. The Context of the Affordable Care Act is a complexity of social dynamics defined by those best informed and empowered. The reader now stands among those entrusted with the most current resources and information. Stay informed. The Context of the Affordable Care Act is a complexity of principles that are intended to safeguard the community wellness on a community-by-community basis. Let your voice be heard as a drum major for social justice and as a metronome facilitating appropriateness for devolution’s pervasiveness. The Context of the Affordable Care Act even in its complexity is simply about creating a caring environment for you and those closest to you. Spread the word! Embrace both the morality and urgency of restorative justice as well as strategies of disparity remediation.

References


Why Environmental Health and Justice Matter
A Response to the Plenary Address of Robert Bullard, PhD

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Author Note
The views expressed in this article are those of the author and do not necessarily reflect the official policy or position of the institutions the author serves.

Abstract
Health is an all-encompassing term that describes more than the absence of disease and expands beyond individuals. It also includes populations or groups as well as the ecosystem. An important component of the ecosystem is the environment—a social determinant of health. Principles of environmental justice require that hazard assessors consider matters of equity and fairness, as well as precaution when considering environmental exposures, particularly in underserved populations that are often disproportionately exposed.

Keywords: ecosystem, environmental justice, precautionary principle

Introduction
Health is a dynamic relationship that involves physical, social, psychological, and spiritual elements that creates well-being (Warren, Lockett, & Zulfiqar, 2002). This definition is broad and all encompassing. It includes individuals and groups, as well as physical and social environments. Social determinants of health include the physical environment in which one lives as well as other factors such as socioeconomic status, access to healthcare, and political circumstances. Environmental justice advocates define the environment in a way that speaks specifically to the communities impacted: “where we work, live, play and worship” (Institute of Medicine, 1999). To attain environmental health is to have freedom from illness or injury related to exposure to toxic agents and other environmental conditions that are potentially harmful to human health. Principles of environmental justice require that hazard assessors consider matters of equity and fairness, as well as precaution when considering environmental exposure, particularly in underserved populations.

Ecosystem health impacts all living creatures
An ecosystem is a biological community of organisms and their physical environment. This includes plants, trees, animals, fish, birds, microorganisms, water, soil, and people, all of which are dependent on each other for optimal health and survival (Begon, Townsend, & Harper, 2005). If one aspect of the ecosystem is damaged or destroyed, other species and elements are impacted. More research is being focused on the human health implications of changes in the structure and function of natural systems and how those changes can affect human health (Myers, et al., 2013). Such research could lead to a better understanding of the human health impacts of ecosystem and environmental change and help to inform decision-making in the land-use planning, environmental conservation, and public health policy (Myers, et al., 2013). However, the literature is replete with evidence regarding ecosystem health on animals. This evidence provides insight into the importance of ecosystem health and the potential impact on human health. For example, the relationship between noise levels and spatial and singing behavior of European Robins was examined (McLaughlin & Kunc, 2013). When the acoustic environment was modified, males were more likely to move away from the noise source as well as to change their singing behavior. This was the first study to demonstrate that not only the presence of noise, but the level of noise pollution is important in a free ranging animal species (McLaughlin & Kunc, 2013). Findings from this research suggests that entities involved in planning of new infrastructure should not only consider physical effects of the infrastructure on the landscape, but also the potential noise levels emitted such that animal habitats are not adversely impacted (McLaughlin & Kunc, 2013). In another study which examined the relationship between mercury deposition, land coverage by coniferous and deciduous forests, and average mercury concentrations in largemouth bass equivalent fish in 14 eco-regions within the south central United States, researchers demonstrated that fish from ecosystems with high atmospheric mercury and coniferous forest coverage posed a significant hazard to human health (Drenner, Chumchal, Jones, Lehmann, Gay, & Donato, 2013). Conifers are trees that produce seeds in cones, grow in areas with warm summers and cool winters, and adequate rainfall, such as the south central United States (Begon, Townsend, & Harper, 2005). Findings from this study suggests that models which use mercury deposition to predict mercury concentrations in fish could be more accurate if the effects of the coniferous forests on deposition are considered (Drenner, Chumchal, Jones, Lehmann, Gay, & Donato, 2013). Mercury, a toxic metal found in aquatic food chains, can be consumed by higher organisms such as humans and wildlife (Environmental Protection Agency) and cause adverse health effects. Results of this study demonstrate that a singular aspect of the ecosystem—a seed-bearing tree—can alter the exposure pattern of mercury on humans and other species, thereby impacting human health.

Another example of a major threat to human and ecological health is exposure to persistent environmental toxicants such as dioxins. Dioxins result from natural sources such as volcanoes and forest fires, as well as anthropogenic sources such as industrial processes like the bleaching of pulp to make paper, the manufacture of herbicides and pesticides and waste incineration (Kogevinas, 2001). Dioxins have a long half-life, are stored in body fat, and increase in concentration up the food chain (Environmental Protection Agency). While gross abnormalities have been observed in animal species following dioxin exposure, little was known about early life stages or on developmental neurotoxicity. Using zebrafish as a bioindicator species, researchers demonstrated neurodevelopmental defects at environmentally relevant levels of dioxin concentrations (Hill, Howard, Stabile, & Cossins,
Making the Environment a Social Determinant of Health

The most direct relationships between ecosystem health and human health are observed in the physical environment. Basic requirements for a healthy environment include clean air, safe and sufficient water, adequate and safe food, and safe and peaceful settlements, and a stable global environment (Yassi, Kjellstrom, de KoK, & Guidotti, 2001). Social determinants impact health not only through behavior, access to healthcare, economic, and political circumstances, but also the environment in which one lives (Satcher & Higginbotham, 2008). Thus the environment, an integral aspect of the ecosystem, is a key determinant of human health. The disproportionate impact of environmental exposures on minority populations has been documented. For example, African Americans, and Hispanics live disproportionately close to toxic and hazardous waste sites and are more likely to live near environmental toxic census tracts (Institute of Medicine, 1999). In toxic census tracts, estimated hazardous air pollutant concentrations were higher than benchmarks (Environmental Protection Agency). Childhood asthma incidence is rising, especially in urban neighborhoods among children with low socioeconomic status (Wright & Giger, 2012). Moreover, researchers have explored how the assessment of disproportionate proximity and exposure has evolved from comparing the prevalence of minority or low-income residents in geographic areas with pollution sources to more refined techniques that use continuous distances, pollutant fate-and-transport models, and estimates of health risk from toxic exposure (Chakraborty, Maantay, & Brender, 2011). Proximity to hazardous waste exposes minority and low-income populations to subsequent adverse health effects in the form of acute or chronic primary health conditions, or as complications to pre-existing medical problems.

Justice requires precaution in the face of uncertainty

When considering the impact of the environment and environmental stressors on individuals and populations, the greatest burden is on communities of concern. This phrase, coined by the Institute of Medicine (Institute of Medicine, 1999), refers to low income and/or minority groups who live, and often work in specific areas or regions. They are further characterized by having real or perceived disproportionately high levels of exposure to environmental stressors resulting in real or perceived adverse health effects. They may also have limited access to health care and education, be politically disenfranchised, have low socioeconomic status, and belong to a racial or ethnic minority group.

Both public health and the precautionary principle embody primary prevention. The principle requires the following: taking preventive action in the face of uncertainty; shifting the burden of proof to the proponents of an activity; exploring a wide range of alternatives to possible harmful actions; and increasing public participation in decision making (Dinneen, 2013). Implementation of the precautionary principle is most critical in communities of concern due to their disproportionate exposure to environmental stressors.

Conclusion

The concept of “one medicine: one health,” originally framed in theory by Dr. Calvin Schwabe (Swabe, 1984), yet put into practice even earlier by Dr. Walter Bowie, former Dean of Tuskegee School of Veterinary Medicine (Adams, 1995), explores the convergence of human health, animal health, and the environment. Presently, the relationship between ecosystem health and human health is being further explored. Meanwhile, ample evidence exists to document the impact of environmental exposures on animal populations, as well as on disproportionately exposed human populations. As a social determinant of health, the physical environment in which one lives must be considered when assessing the health of a population. When faced with uncertainty about exposure risk, precaution should be used. Principles of environmental justice require that hazard assessors consider matters of equity and fairness, as well as the precaution when considering environmental exposure, particularly in underserved populations. This suggests that environmental health and justice really do matter when addressing the human health of minority and other underserved populations.

References


Community Engagement, Organization and Development for Public Health Practice

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Abstract

The rise in health risk among disparate population groups is of paramount concern to the health status of the United States. The new millennium’s social determinants bring about the need for immediacy in educating the health practitioners (i.e., students and leaders) of today and tomorrow. Also, it is vital that there be venues for the continuing education of professional public health practitioners presently working at the “grassroots” community level. It calls for the renewing and redefining of terms and concepts such as community engagement, community sustainability, community resilience and community partnership. Also, it calls for learning how to design community-based translation strategies that are new and appropriate for addressing and reducing high-risk behaviors and occurrences in disparate communities.

Keywords: community engagement, trust, displacement, equity, healthy community, feral, faith-based, form coding, proximal, distal

Introduction

Inequitable distribution of social, economic, and environmental resources demand new and renewed means of building strong community-based partnerships. This calls for a renewed community engagement, organization, and development (CEOD) implementation, with its grassroots empowerment focus. The traditional concept of CEOD must be modified to more effectively engage people and organizational leadership in disparate and all other communities. It must seek to emphasize the importance of nontraditional approaches, partnerships and translation methods based on the 21st-century impact on community change. Discussions in this presentation are based on recent real-life community-based health intervention programs, community organization approaches and methodologies, global strategies and other theoretical frameworks from relevant scholars are shared.
Community Engagement, Organization and Development (CEOD) Model – Key Components

Discussion will focus now on the key components, theory and practice of the CEOD Model critical to the community development process.

Community Engagement

Community Engagement (CE) can be identified in two separate ways. The first, termed Informal Engagement, involves taking proactive approaches to spontaneous conversation(s) with community residents about their community. This spontaneity can only occur if one is in the community on an ongoing basis, and will almost always result in identification of formal or informal.

The second, Formal Engagement, involves formally contacting community leaders (gatekeepers) respectfully seeking scheduled visits with them in their offices, places of business, residences or in any other setting they designate. In some cases telephone calls will suffice; however, face to face contact is always recommended, as it is the most effective method of engaging when seeking to build trust.

If public health practitioners are to be fully engaged with a community, on a formal or informal level, they must become both prepared and actively involved. Such engagement means working with communities over extended periods of time, and truly edifying them into public health awareness and education. (Murphy, 2012)

Building Trust, Respect and Credibility

The public health practitioner should always show respect for the core values and beliefs of the community they are seeking to enter. Credibility and Trust are core values in the relationship building process, and should be seen as the glue that holds things together. Examples of key considerations when attempting to build credibly with community leaders/members include, but are not limited to, the following:

1) Respect: Exercising respect is the most essential interwoven ingredient in the relationship building process. This underpinning element must be established before one can effectively proceed toward developing community engagement. It is the first step in genuinely getting to know people.

2) Interpersonal Relationships: If credibility and trust are to occur, it will be important for the community organizer/health professional to have established interpersonal relationships with key individual community members and leaders. Again, this takes time to build, and will only happen with ongoing tactful, face-to-face engagement involvement. Showing genuine concern about the individual’s and community’s well being can be an invaluable first step towards building a trusting relationship.

3) Cross Community Referrals: As initial relationships are established, referrals will be made across the community from ‘one community leader to another community leader’ (horizontal referral). This is a very important step in the process of building community credibility, as these type referrals may open doors leading to trust and credibility.

4) Community Participation: It is also important to show up and participate in scheduled and unscheduled community activities. This includes attending community activities that have nothing specifically to do with health or the leading causes of death, and are not initiated by the public health practitioner.

5) Identifying Resources: Credibility can be further enhanced by assisting the community to conduct some of its pre-planned community activities. A general principle applicable to both this and later stages of the CEOD process is: it is essential to address the community’s priorities first.

6) Initiating Community Activities: The public health practitioner can volunteer to assist community members to plan and conduct a health-related activity. In doing so, he/she can identify and arrange for professionals (vertical referrals) that have specific skills and trades to participate.

It is worth repeating here that, in order for the CEOD process to have a chance, there must first be respectful, trusting and credibility relationships formed. These exist throughout CEOD building process, they will serve as invaluable ingredients to CEOD sustainability and resilience.

Servant Leadership

Basically, service covers two areas: Servanthood and Servant Leadership. The concept of servant-leadership appears to be so complex as to defy simple definition – it is multi-dimensional, rich in hues and wide-ranging in its meanings. In servant-leadership, self-interest gives way to collective human development. Servant-leadership is an attitude toward the responsibilities of leadership as much as it is a style of leadership (Hall 1991). Servant leadership should also be viewed as stewardship. Stewardship also involves service to others and being willing to share anything that might benefit and edify another including: skills, time and talents. It elevates service above ones education, position, wealth or fame. With respect to servanthood the leader develops and empowers the community residents, who then, in turn, assist the leader to edify the community. The focus here is on the leader’s character and desire to serve. Being just a service-oriented person, in the traditional notion of servanthood, does not qualify one as a servant leader. However, servanthood can be viewed as the first phase to servant leadership.

In summary, with servant leadership and servanthood, the leader seeks to edify the community by effectively recognizing community residents as valuable resources; the emphasis here is on leadership skills, such as vision-casting and team-building. For the purposes of the CEOD process, there are three basic elements that can assist the professionally trained Public Health Practitioners (PHP) to be an effective servant leader. These include:

1. Character Development;
2. Engagement and Involvement, and;
3. Impacting Community and Culture
The psychology of displacement, as an intricate part of any renewal process, speaks to the usurping of environmental, cultural and territorial attachment. The disorientation and alienation brought on by displacement leads to adverse psychological, physical, economic, and social effects. The definition of the term place is linked to what can be termed the Critical Three: attachment, familiarity, and identity. For many cultural groups, displacement initiates the unraveling of these critical three, precipitating the public health illnesses of territorial and psychological disorientation and alienation.

As underlying aspects of displacement, the Critical Three can have a synergistic impact (Fullilove, 1996). As national, state and local leaders of the 21st Century attempt to rewrite the relocation process, policies must ensure that displaced individuals, and their families, have access to basic human needs including: food, housing, transportation and access to medical facilities for appropriate health care (Harris & Kaye, 2004).

**Form Coding**

Form-Based Codes create a predictable public realm by controlling physical form primarily, and land uses secondarily, through city or county regulations. Such regulatory changes drive lifestyle, behavioral, and cultural patterns such as: who lives in the community, how one lives and works there, who buys and sells there, and what artifacts are used to symbolize the community. (Form-Based Codes Institute, 2004).

**Gentrification versus Regentrification**

Gentrification is phenomenon in which low-cost, physically deteriorated neighborhoods undergo physical renovation with an increase in property values, along with an influx of wealthier residents who may displace the prior residents, many of which are population groups of disparity status.

The Creative Class

The Creative Class refers to: a mobile elite whose upscale lifestyle preferences increasingly shape the geographies of economic growth.

Communities are highly impacted by a Twenty–First Century in which urban renewal and rebuilding is rapid and ramped. This urban renewal is accompanied by an aggressive migration of middle class and affluent populations into historically deteriorating inner city areas, often results in displacing lower income residents whose families have resided there all their lives. Ironically, this renewal brings with it the increasing interconnection of people and places as a result of advances in environmental reconstruction, transport, e-communication, and other information technologies that causes political, economic, and cultural convergence. Through policies and structural transformations in city governments, a phenomenon is occurring in which low-cost, physically deteriorated neighborhoods undergo physical renovation and an increase in property values, along with an influx of wealthier residents who may displace the prior residents, many of which are population groups of disparity status.

Unfortunately, this process of renewal and revitalization of the inner cities, in most cases, results in uprooting of the urban poor by raising rents and taxes and making it impossible for them to stay. Low income neighborhoods are potentially attractive neighborhoods, with solid housing stock and well laid-out streets in close proximity to the city center, are being discovered by developers, investors, artists, and other professionals. Block by block these neighborhoods are rapidly changing, as newcomers go about fixing up old buildings. As galleries and cafés open, curb stores and mom ‘n’ pop groceries close. City services improve and the infrastructure is revitalized. In the final phases, wealthier and educated groups begin to migrate in and dominate the once predominately low income and African American communities. Thus the sequence: Reassessments of property values, revision of actuarial tables, and explosive tax bases and insurance premiums all have a coercive impact on the traditional residents of the community. From a strictly economic viewpoint, an increase in the tax base, improvement in site infrastructure, and lowering of crime reflect positively on city officials as property values rise, followed by property taxes and rents. (Florida, 2002)

**Feral Cities vs Healthy Communities**

The very term feral city is both provocative and controversial. The phrase suggests, at least faintly, the nature of what may become one of the more difficult security challenges of the new century. A feral community is (or would be) defined as: a metropolis with a population of more than a million people in which the government has lost the ability to maintain the rule of law within the city’s boundaries, yet remains a functioning actor in the greater international system (Norton, 2010).

Conversely, we have the concepts of Healthy Cities or Healthy Communities. Under the Healthy Community definition four distinct categories are identified including: government, economy, services and security. They are defined as follows:

**Government or Healthy Leadership:** Strong political leadership in place with the ability to govern and set meaningful policy for the community.
Healthy Economy: A productive mix of internal and external health resources, primary care services, manufacturing activities, and a robust tax base.

Healthy Community Services: A complete array of essential community services, providing public education, equitable access to health services, and culturally relevant programs and projects to their populations.

Healthy Security and Emergency Services: While not crime free, is well regulated by professional and ethical public safety services (police and fire), able to respond quickly to a wide spectrum of threats.


Social Capital –Proximal and Distal Measures

Social capital measurement is considerably complicated by the fact that social capital research and evaluation have frequently relied upon measures of the outcomes of social capital as indicators of social capital itself. Indicators used in social capital research can be classified into proximal and distal groupings. Proximal indicators of social capital are, in fact, outcomes of social capital related to its core components of networks, trust and reciprocity.

Examples of proximal outcomes (or indicators) include the use of civic engagement as an indicator of social networks. This approach was made famous (Putnam 1995, 1998) in analyses of civic decline in America, which were based upon membership of formal associations and groups. Actions associated with a display of confidence in others, an outcome of a norm of trust (Onyx and Bullen 1997,2000), as well as reciprocal acts or exchanges, an outcome of a norm of reciprocity (Rose 1999), are also used as proximal indicators of social capital. Distal indicators are outcomes of social capital that are not directly related to its key components. Examples of distal indicators, drawn from a study of social capital and health, include: life expectancy, health status, suicide rates, teenage pregnancy, crime rates, participation rates in tertiary education, employment and unemployment rates, family income, marital relationship formations and dissolutions, business confidence, job growth, growth in GDP and balance of trade (Spelberger 1997).

Both proximal and distal indicators are relied upon frequently in social capital research, particularly in studies reliant upon secondary analyses, where existing data is limited. However, empirical investigations that rely upon indicators of social capital are rarely supported by direct empirical investigation of the relationship between indicators (proximal or distal outcomes) and the core components of social capital. Hence both proximal and distal outcomes may or may not be valid indicators of social capital for this reason. This raises the further tautological problem that research reliant upon an outcome of social capital as an indicator of it, will necessarily find social capital to be related to that outcome, without empirical means to explain why, or indeed whether, this is so. Social capital becomes tautologically present whenever an outcome is observed (Portes 1998; Durlauf 1999).

Faith-based Values

Holmes addressed how to effectively and ethically engage faith-based communities, and proposed a model to work efficaciously in diverse faith based communities (Holmes, 2007). This chapter focuses on health as an example of a salient issue in all communities, because health impacts every level and each life stage of the human experience. Furthermore, health is described as “a relationship, a dynamic interplay between the physical, social, psychological, and spiritual well being of the individual and the group and their interaction with the physical and social environment.” Describing health, in this manner, highlights several constructs such as the importance of relationships for human health; the group, as well as the individual, being essential for human health; spirituality and its relationship to human health; and the physical and social environment as critical influences on human health (Warren, Lockett, Zulfikar, 2002). Health disparities are targeted by many community-based organizations, including faith-based communities. The chapter also provides the opportunity to review several cogent faith-based theories and practices, while discussing the how to apply certain theories to the community origination and development process. (Warren, 2012)

Health Equity

Equity or fairness is a key value that cannot be ignored in an attempt to level the playing field among population groups. It is an intricate part of the respect, justice and beneficence rubric and points squarely at the heart of any country’s value system.

Health equity can be defined as “the fair distribution of health determinants, outcomes, and resources within and between segments of the population, regardless of social standing.” Health equity may never be realized fully by disenfranchised groups, because in many cases, for those at the bottom of the totem pole: the middle class pays, the rich get the benefits, and the poor get the blame.

In America, equal rights are available to everyone, but equal rights and equal opportunity are different concepts. It is critical to recognize this truth in the realm of public health, as more and more people develop vulnerabilities and chronic diseases, and require expensive health care services (Cruz, Murphy 2004). A large portion of the problem of health inequity centers on the growing disadvantages arising for low-income populations living in the inner cities. Trends, such as are brought on by both globalization and gentrification, affect public health, raising steep challenges for public health providers, and the communities and cultures they serve. Some of the first fruits of 21st century socio-economic globalization are lack of access, displacement, higher taxes, psychological devastation, cultural change, tradition fragmentation, and threat of the loss of health care. They exclude lower economic class population groups from quality lifestyles, and have a direct impact on the health of individuals and communities. In many cases, however, community residents are not as concerned about their health care delivery system as they are about their health and the health of their families (Benzeval, Judge and Whitehead, 1995).

The impact of non-medical services and resources indirectly influence the determinants of health. These include, for example, services providing access to education, housing, employment, social and leisure opportunities, consumer goods, and social support, as well as measures to control the physical quality of the environment (McKeown, 1979; Curtis and Saket, 1996).
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Human Embryonic Stem Cells:
Microscopic Agents for Scientific, Religious, and Bioethical Change

Response to the Plenary of Dr. Charmagne Beckett

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Abstract

How can society define a space where faith-based ethics and scientific research intersect and are in dialogue with one another? Historically, science, technology and medicine have social, cultural, and religious implications that extend far beyond the laboratories in which scientific knowledge is generated. One particular area of production of scientific knowledge is the human embryonic stem cell (hESC) field. Human ES cells have been intensely debated since being discovered and reported to the scientific community in 1998. For many Christian communities the moral status of the embryo calls into question the morality of hESC research overall. What further complicates this issue is the understanding that religious communities place great value on healing the poor and disadvantaged members of society in an effort to alleviate an individual’s suffering from incurable illness and disease. However, despite the promise of stem cell research to aid in advancing medical treatments, there are major ethical and theological reasons for religious opposition. Therefore, this paper aims to begin establishing a framework that supports dialogue and collaboration between religious and scientific communities about boundary-crossing entities produced by science and technology. In so doing, scientific and public policy discourse within the U.S. surrounding hESC research is examined, Catholic moral thought and theological teachings are presented, and ways to forge pathways to partnership between the communities are recommended.

Keywords: human embryonic stem cells, bioethics, religion, stem cell policy

Author Note

The views expressed in this article are those of the author and do not necessarily reflect the official policy or position of the faculty, staff, administration, students or any affiliated individuals with Harvard Divinity School and Harvard University. This subject material is a preliminary presentation of ideas being developed in a master’s thesis.

Acknowledgements: It was truly an honor and privilege to have the opportunity to experience the sharing and exchange of thought-provoking ideas at the 2013 Public Health Ethics Intensive. I sincerely thank Dr. Reuben Warren and the entire faculty and staff of the Tuskegee University National Center for Bioethics for the phenomenal course.

Introduction

Science, law, and religion are deeply embedded within a matrix of intersecting and competing ideals, interests, beliefs, values, and networks of actors. These constructive elements come together and work in concert to construct our society, while shaping the ways in which we produce knowledge, assign authority, and accept truth. As such, it follows that historically, science and technology have had legal, social, and religious implications that extend far beyond the laboratories in which scientific knowledge is generated. One such example is the human ESC research field, which has been intensely debated in the U.S. by scientists, lawyers, religious leaders, politicians, and the public since 1998. However, driving deeper into the contextual background, the history of this debate originated decades earlier when biomedical research involving human subjects and fetal tissue incited theological objections centered around the fact that human life, even its earliest forms, should be treated with dignity and given equal protection as human beings from harm and exploitation. This type of discourse points to the fact that the spheres of biomedical research and religious and bioethical thought are intersecting more than ever, raising new questions about whether there exists space for a bioethical framework that gives equal relevance to faith-based reason.

Before proceeding to detail how to develop such a space, it is important to understand both the history of stem cell research and the development of a discourse around it. An important aspect of the discursive space that I envision between science and faith-based ethics involves a clear understanding of each viewpoint, its history, and what is at stake for each position. It is also vital to establish foundational questions that frame this paper. Some of these foundational questions include: 1. What are the interactions between the institutions of science, religion, law, and policy within the stem cell debate; 2. How have these institutions with their knowledge production, major actors, and language shaped the different meanings of stem cell research for the public; and 3. How has the stem cell debate impacted, influenced, and challenged the public’s understandings of regenerative medicine when law and policy are tasked with resolving bioethical controversies? In so doing, I will present a comprehensive history of key scientific and policy milestones that have undoubtedly shaped the way the stem cell debate has developed and taken center stage in many political, bioethical, and religious discussions. From Roe v. Wade to the National Research Exchange Act to the Dickey-Wicker Amendment to the founding of embryo adoption agencies, these events thematize how life is being conceptualized by multiple groups and provides fertile ground for investigation. Secondly, I will present perspectives offered by the Roman Catholic Church on stem cell research as communicated through documents released from the Vatican, Catholic moral theologians, and the U.S. Conference of Catholic Bishops. These perspectives include specific moral and theological objections to the destruction of human embryos, natural law theory, and the theology of human dignity. Lastly, I will explore constructive ways that both communities can create such a space where multidisciplinary dialogue can take place in an effort to produce a paradigm shift in the way both communities respond to each other.

As a scientist and ordained minister, this unique position provides me the opportunity to investigate this matter with the hope that society can enter into the liminal space that exists between science and faith-based ethics. I would like to lay the foundation for depolarizing the viewpoint that science and religion exist on opposite sides of the spectrum. With this work, my intention is not to present ideological arguments about the beginning...
of life, human ensoulment, and the biological and moral status of the embryo; nor is it my
goal to present a case for or against human embryonic stem cell research. Rather, this paper
can be read as an open invitation for all invested communities to enter into a respectful and
honest discussion over these issues. As scientists, religious leaders, ethicists, policymakers and
the public so often seem to talk past one another, this paper aims to provide the groundwork
for a secondary language and rules of engagement for the purpose of creating a space where
multiple groups with such different histories and perspectives can fruitfully engage with
one another. With the understanding that the Roman Catholic Church is not a monolithic
community, I have chosen to focus on this religious tradition on account of both its wealth
of published engagement on the matter and its significant influence upon the discourse
surrounding human embryonic stem cell research in the United States.

Science and Policy

The Science behind the Controversy

Dr. James A. Thomson of the University of Wisconsin first discovered in 1998 that
human ES cells can be harvested, cultured, and maintained in vitro indefinitely. They are
derived from the inner cell mass, a group of approximately thirty cells, of four or five day
old embryos that have developed into blastocysts collected for in vitro fertilization (IVF)
purposes (Thomson et. al, 1998). Human ESCs are pluripotent cells meaning they are
capable of unlimited and undifferentiated proliferation in vitro, maintain normal karyotypic
characteristics, sustain high levels of telomerase activity, and retain uniform undifferentiated
morphology in prolonged culture. In addition, hESCs have the ability to differentiate along
the three embryonic germ layers in vivo as evidenced by teratoma formation after injection
into severe combined immunodeficient (SCID) mice. They have also been shown to express
certain cell surface markers that are widely used to confirm pluripotency, such as stage-
specific embryonic antigen SSEA-4, TRA-1-60, TRA-1-81, and alkaline phosphatase (Brown
et. al, 2009). Oct-4, a transcription factor, has been identified as another key indicator of
undifferentiation. In order to maintain pluripotency, hESCs are cultured on a variety of
substrates. Historically, mouse embryonic fibroblast (MEF) feeder layers were the primary
substrate, however, extensive progress has been made in the direction of culturing cells in
clinically relevant feeder-free microenvironments such as hydrogels (Villa-Diaz et. al, 2010).
In addition, the cells are grown under serum-free conditions using serum replacement (SR)
with supplements of basic fibroblast growth factor (bFGF). Under these culture conditions,
continuous passaging of hESCs is permitted while maintaining pluripotency and normal
karyotypic characteristics. In 2007 there were only 22 available hESC lines for research,
however, now there are 254 different lines approved on the NIH Stem Cell Registry (NIH
Stem Cell Registry, 2013).

Regenerative medicine is a field of biological research that is based on the principle
of restoring function and replacing diseased tissue through the use of stem cells, and the
application of biological and engineering principles to solve these problems. It has been
hypothesized that hESCs may become the basis of therapeutic strategies to treat diseases such
as diabetes, heart disease, Alzheimer’s, and Parkinson’s disease. Currently, the major goal for
hESC is the controlled differentiation into specific kinds of cells for the purpose of replacing
or regenerating damaged tissue. In general, stem cell research advances the knowledge about

how an organism develops and how progenitor cells migrate from the stem cell niche to the
site of damaged or diseased tissue. Although this overall goal seems scientifically promising,
the U.S. is divided on the issue of the morality of the destruction of human embryos for the
derivation of hESCs, with sharp differences in opinion about law and policy between liberals
and conservatives that reside in both the scientific and religious camps (George et al., 2008).

Human ESC Policy – A Historical View

On the other hand, advocates of stem cell research promote promises of revolutionary
clinical treatments for congenital defects, injuries, disease, and much more. Therefore,
the federal and state government should provide financial initiatives to aggressively pursue this
unprecedented opportunity. On the other hand, opponents assert that stem cell science and
technology is an attempt to rewrite the laws of nature, and to some, to assume the role of the
Creator. It then follows that public funding that confers government sanction of the
research should be halted immediately. Hence despite the reports on the enormous benefits
of stem cell research, there has been a tremendous amount of congressional and legal activity
surrounding the legality of the research. Given the different viewpoints and assertions, before
addressing the religious perspectives it is prudent to look at the historical and contextual
background of how the U.S. defined the biological and ontological status of the human fetus,
and how it relates to the status of the human embryo. And upon even closer inspection,
the religiously charged language that is utilized throughout the legal history further points
to the fact that science and religion are inextricably linked. As such, I present the following
brief timeline that is representative of key scientific, legal, and policy moments as it relates to
abortion, and federal funding for fetal tissue and stem cell research. Historically, these events
date back forty years (Fletcher, 2001; Wertz, 2002; Vogel et al., 2010):

- **January 1973** – In the historical *Roe v. Wade* case, the Supreme Court decided with a
  7-to-2 majority vote in favor of Roe, deeming abortion a fundamental right where
  a person has the freedom of choice according to the 14th Amendment. The human
  fetus is not a person until it is viable around 24 weeks of gestation, and capable of
  living outside the mother’s womb.

- **July 1975** – Taking into account the work of Richard McCormick, a leading
  Catholic moral theologian, the National Research Act was passed and research was
  encouraged because of its great potential benefits. However, funding was limited.
  On account of McCormick’s principle of equal treatment, fetuses to be aborted
  and delivered were to be treated the same. Despite *Roe v. Wade*, this report essentially
  assigned primary rights of societal protection to the fetus as a human being. After
  the report, the NIH lifted its moratorium on fetal tissue research.

- **May 1979** – The EAB approves federal funds for in vitro fertilization (IVF) and
  embryo transfer up to 14 days. Despite this approval, a moratorium on such
  research is enacted and the Department of Health and Human Services (DHHS)
  withholds federal funding.

- **November 1985** – The National Research Exchange Act (Public Law 99-158) was
  passed under the Reagan Administration, which included a change to the original
  guidelines. Any fetus, whether living or aborted, could not be subjected to any level
  of risk. This stipulation effectively ended federal support of fetal research.
Plenary Responses

November 1994 – The NIH Human Embryo Panel report rejected the position that embryos have the same moral status as persons, but respect could be shown to embryos by limiting the time frame and the purpose of the research. Although they support federal funding, religious public outcry prompts Clinton to override the Panel’s decision but does allow very limited embryo research.

January 1996 – Republican-led Congress passes the Dickey-Wicker Amendment, banning “research in which a human embryo or embryos are destroyed, discarded, or knowingly subjected to risk of injury or death greater than that allowed for research on fetuses in utero”. This amendment has been the legislation used for every lawsuit against the U.S. government for federally funding stem cell research.

November 1998 – Dr. James A. Thomson at the University of Wisconsin first isolated hESCs from embryos (using private money) and published his findings in Science. President Clinton requested the National Bioethics Advisory Commission (NBAC) turn its attention back to hESCs.

August 2001 – In a public address to the nation, President Bush announces Executive Order 13435. It requires that the NIH only fund research on stem cell lines already derived and listed on the NIH Stem Cell Registry.

July 2004 – The Senate passes a bipartisan bill known as the Stem Cell Research Enhancement Act, which would allow federal funding for hESCs derived from surplus embryos donated by couples from IVF clinics. However, in July 2006 President Bush vetoes the bill.

March 2009 – President Barack Obama issues Executive Order 13505, stating the NIH can responsibly conduct and support research on human stem cells (including hESCs), and that it must develop new guidelines and criteria for approval to the NIH Stem Cell Registry.

June 2010 - April 2012 – Chief Judge Royce Lamberth of the U.S. District Court grants the plaintiffs’ request in the Sherley v. Sebelius case for a preliminary injunction that places a ban on all federal funding of hESC research.

November 2012 - January 2013 – Sherley attempted to have the case seen before the U.S. Supreme Court but that appeal was denied and the ruling that funding for hESC through the NIH was unconstitutional has been overturned. James Sherley of the Boston Biomedical Research Institute in Watertown, Massachusetts, says that the decision will not end his efforts “to emancipate human embryos from research slavery sponsored by the NIH” (Wadman, 2012).

These major moments demonstrate how the U.S. has tasked Congress and the legal system to resolve moral and religious arguments about human dignity and the beginning of life. These policy decisions have both expanded and constrained the public’s control over research and development, redefined and altered the view of the human embryo, shaped the public’s freedom to hold beliefs that are incompatible with scientific knowledge, as well as defined the public’s freedom to hold values that are incompatible with traditional religious doctrine. However, to get an even fuller view of the complex concepts at stake, the current religious and theological viewpoints on the matter must be examined.

Religious Perspectives

Correlative to the tremendous growth the field of hESC research has experienced over the past decade, so too have theological responses and criticisms of the research proliferated, especially amongst the Roman Catholic Church. Why is the Catholic voice so important? It is important because despite the predominance of Protestant ideologies that were influential in the founding of the United States, according to the 2011 Yearbook of American and Canadian Churches, the Catholic Church is now the largest single denomination in the U.S. with approximately 68.5 million members (National Council of Churches, 2011). Although to date former President John F. Kennedy has been the only Catholic president, Catholic representation within this country as an important political voting block cannot and should not be taken lightly. The American Catholic Church, which is considered to be in full communion with the Roman Catholic Church’s doctrinal beliefs, has long been at the forefront of such social, religious, and political debates within the U.S. From developing an extensive Archdiocese school system starting in the post-Civil War period that persists well into the 21st century, to the Catholic worker movement, and then to its commitment to righting social inequalities in education, healthcare, and poverty, the American Catholic Church has strong political influence (Williams, 2002). Thus, given the history, the notion of creating a space and place for religious and political debate about a controversial topic such as hESC research is plausible and necessary.

From an article written by the Vatican for the Pontifical Academy for Life and a policy statement from the U.S. Conference of Catholic Bishops, the scientific and therapeutic use of hESCs poses two major ethical problems for the Church. The first main ethical issue is that it is not morally licit to use live embryos for hESC production because of reasons such as: 1) the human embryo is a human being with a defined identity, therefore, it is not a collection of cells and cannot be treated as a mere object of research; 2) the collection of the inner cell mass will irreparably damage the embryo; 3) the human embryo is an individual that has the right to life and cannot be violated or killed; 4) moral theology states that the theory of probabilism does not apply; and 5) embryos have become sacrificial victims predestined to be immobilized on the altar of scientific progress. The second ethical issue is that it is not morally licit to use or conduct research on differentiated cells from commercially available hESC lines because: 1) the morally illicit intention of destroying a human embryo does not excuse the use of commercially available cells; and 2) humanitarian efforts to finding cures for diseases do not outweigh the ethical risks (Donum Vitae, 1987; Doerflinger, 1999; Corea, 2000).

When determining what the current state of policy discourse is about, it important to understand that embedded within Roman Catholic arguments is one major concept – the Catholic natural law theory of faith and reason. As previously stated in the timeline section, we see the same issues raised for abortion and fetal tissue research in the 1970s and 1980s. This is because at the center of the debate is the idea that life and human dignity begins at conception. Therefore, the inviolability of human life is often times used in an absolutist sense as a conversation stopper (Mendiola, 2001). In alignment with the theology of dignity, Pope John Paul II stated that “dignity and the right to life begin at the moment of existence” (Vestal, 2008). To secular ethicists, the central question that is being debated surrounding the Dickey-Wicker Amendment is whether there is a distinction between the embryo and the pluripotent hESCs derived from embryos. On the other hand, Catholic theologians make no
distinction between the two entities, because the relationship between embryos and hESCs is inextricably linked (Parens, 2001). Furthermore, the Catholic Church believes that natural ontological and moral boundaries assign dignity and citizenship to embryos, prohibiting them from being manipulated and destroyed (Metzler, 2001). However, the Roman Catholic moral tradition can sometimes offer a multiplicity of perspectives. Contrary to popular belief, it is not a homogenous and singly unified group on all matters of social, educational, political, and scientific consequence. Although they agree on God's deep love for the world, their commitment to help the poor and disadvantaged, and respect for human life, there is some disagreement amongst moral theologians, church leaders, and laity. This is due in part to the fact that the core of Catholicism is the tradition's understanding of natural law, which tells a person of reason and faith to look to the concrete reality of the world in order to make a decision about specific moral rules and circumstances (Farley, 2001).

Human reason and observation of the concrete reality of the world allows people to determine how to respect each created human being. Therefore, it follows that issues of assisted reproduction, fetal tissue and hESC research are topics that not everyone within the Catholic Church agrees upon. There is a certain level of reason embedded in social teaching that encourages a person to reflect on contemporary and ever-evolving social and political life. And it is these specific social realities that allow room for changes in thinking, and changes in rules about specific moral conditions (Mendiola, 2001). Although Scripture represents divine authority, the continuing process of discernment and deliberation about the intelligibility of realities that takes into account the best scientific knowledge available may perhaps allow Catholics to adopt an “ethics of toleration” mode of thinking. Such a perspective then situates a person of faith and reason to make difficult choices when competing values arise from specific moral conditions. Michael Mendiola, professor of Christian ethics, suggests that perhaps hESC research is the type of situation where “drawing on the notion of toleration operative in Catholic moral theology” might be useful in order to engage in debate in a “manner that is consistent with the principle of the inviolability of embryonic life, but not exclusively dependent on it as a stop-the-discourse argument” (Mendiola, 2001).

These theological concepts and viewpoints expressed by the Catholic Church and other religious communities point to the complexity of the issue and the necessity to establish a framework that supports exchange of ideologies across disciplines, and reasonable solutions. This debate has undoubtedly brought new theological and philosophical insights to the forefront as it relates to advances in our understanding of human development and regenerative medicine. The theology of human dignity presented by the religious communities challenges the scientific community to address the different forms and stages of life that embryos, and subsequently stem cells, can embody. Within the laboratory environment, what does it mean to research, manipulate, and influence life at this level? This is a question to keep in mind on this ethical journey that is biomedical research.

When biomedical research produces knowledge that raises new theological questions, the religious community (and society as a whole) is challenged to develop definitive boundaries and classifications for biological entities. Biological entities, such as excess embryos, are an example of a boundary-crossing product of biotechnology, where ontological surgery must be performed (Jasanoff, 2011). As a result of these types of entities, the field of science and technology studies (S&TS) has been brought to the forefront in bioethical discourse. Inherent in S&TS is that one of its primary concerns is the investigation of the structures, practices, ideas and material products of knowledge societies, where links between knowledge, culture and power are extremely useful. One of the domains of such research is the theory of co-production, which suggests “the ways in which we know and represent the world are inseparable from the ways in which we choose to live in it” (Jasanoff, 2004). Additionally, “co-production comes into focus as different forms of authority are constituted, embodied, challenged, and restabilized”. Therefore, it follows that within a complicated network of actors within the government, universities, lawyers, researchers, and the public, it is difficult to make immediate decisions about the ways we choose to incorporate innovations into the society we live in. It also becomes difficult to decide which form of authority will set the social order. In this particular instance with biomedical research, ethical frameworks do not easily map onto what actually happens in practice. One has to look at the topography of a given situation and the legal landscape surrounding biomedical advances in order to determine the ways in which ethical considerations – both secular and faith based – should intervene.

Within the scientific community, there is a culture of skepticism where scientific information is regarded as absolute truth once repeatable results are placed under serious scrutiny and investigation, and a statistically significant p-value is obtained confirming the new information. Therefore, if one looks at the scientific community as a producer of authoritative knowledge, the majority of the conversation about ethics takes a very different turn from that in a religious context. New social contracts, property rights, patent rights, ownership, autonomy, ontological and biological classification, doctor-patient and client-consumer relationships, the understanding that it’s the state’s responsibility for life to be enacted through law and policy (bioconstitutionalism), and private sector economics are major aspects of ethical debates surrounding the public good (Jasanoff, 2005 and 2011). However, following discursive analysis of the various religious arguments, it is apparent that certain ideologies, concepts, and terms are missing from their construction of the problem. When the religious community is considered producers of authoritative knowledge, some of these terms simply are not there – such as client-consumer relationships, the private sector, property rights, and bioconstitutionalism to name a few. According to the conservative Catholic position, there is no ontological distinction between the pre-embryo and the embryo, and the discarded embryo and the implanted embryo. This once again points to the question of how can biomedical research and faith-based ethics intersect with and inform one another.

As a thought experiment, it would be interesting to introduce certain ethical values of non-religious origin into religious discourse in order to raise a few thought provoking questions for secular and faith-based ethicists alike. How might the Catholic Church take
to the concepts of being donors and not just parents, ownership over embryos as property, embryos being classified as biological parts, and entering into a social contract with the public when deciding to utilize IVF techniques that will invariably produce surplus embryos that can be used to benefit science? Or do these concepts have much relevance at all to the Catholic community (and religious communities as a whole)? This is related to issues of co-production because we have yet to determine where human embryos fit within our society, due in part to the fact that the authority of science conflicts with the authority of religion. Given the fact that the Catholic Church regards the Bible as the divinely inspired Word of God, the moral thought and work produced from this particular religious body is thought to have as much authority and – and if not more than – the secularized scientific body. If there are two competing bodies of knowledge production, does it matter how they both define the ontology of the pre-embryo and the embryo? Can the communities ever co-exist and collaborate? What kind of common secondary language might facilitate these necessary conversations? In essence, is the gap between science and faith too wide to overcome linguistic barriers of communication?

As society forges pathways to partnership on a multitude of issues, instead of letting failures and controversies drive reform, it is prudent to learn from past mistakes and develop ways to collaborate on addressing salient bioethical, policy, and religious issues. The recommendations for collaborative partnerships described here must be authentic, and they must engender mutual trust between both communities.

Conclusion

Shall science ever complement religion; will religion ever complement science? And dare we even ask, can these competing, society-ordering institutions of knowledge and authority ever come to an agreement on the stem cell issue? The answer is simple and straightforward: No. However, there are places of intersection; places where these elements cross paths and provide ample material for new scientific, legal, theological, and ethical questions. The appropriate relationship between them is not easy to determine, if there should be even an established relationship at all. But the reality is that every U.S. citizen has the right to political participation and furthermore, the right to participate according to their own values and belief system. Whether those values are rooted in or influenced by scientific evidence, democratic justice, or belief in God, everyone is entitled to incorporate them into their political decisions. Taken together, this article sought to integrate stem cell production because we have yet to determine where human embryos fit within our society, the separation between science and faith is not as vast as one might have assumed. If the U.S. plans to move forward with current and future biotechnological discoveries, we must begin to establish a framework and create a space that will engage the scientific and religious communities to be in dialogue with, as opposed to against, one another. If instead the conversation is reframed where not the separation, but rather the intersection of science and faith-based ethics is discussed, then both communities can begin to have constructive conversations where pathways to partnership will be everlasting.

References


**Plenary Responses**


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**REVIEWS**

As we bring this special edition to a conclusion, one should ask: Where do we go from here? What is the long-range impact of what we have just read? This section contains three reviews that bring these important questions to our full attention.

In the book review of *Freedom Flyers, The Tuskegee Airmen of World War II*, we are asked to keep in mind that the Tuskegee Legacy is expansive in so many ways historically and into the future.

In the film review of *The Invisible War*, we are reminded that there are untold numbers of diverse issues of social justice in our own time. Are we aware of these needs in our local communities, our nation, and our world? Are we ready to face them and work for social justice in our own time in so many emerging areas?

In the film review of *Ethel*, we are made deeply aware that the call to social justice has a price on one’s inner self. Are we prepared to become agents of change in our society? Are we ready to be changed ourselves in what we do and who we are called to be?
Book Review

Freedom Flyers - The Tuskegee Airmen of World War II (2010)

J. Todd Moye


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Author Note

It is to be noted that the author was Commander of the 332nd Expeditionary Medical Group, The Red Tail Medics. This is the 2nd generation of the nationally famous “Red Tails Wing” that is the subject of the book review that follows. Building upon its profound legacy for the struggle of human rights in America, by the time of this author’s leadership of the medical group, Red Tails had become a model of equality and diversity among all of the Armed Forces. The author is a federal employee and a member of the United States Armed Forces. Therefore, the views and opinions expressed in this review are solely those of the author and do not reflect the official position or policy of the United States Department of Defense, or the U.S. Government.
Reviews

Introduction

Tuskegee is far more than just a place. More deeply, it is an “Experience.” When we hear the phrase, “The Tuskegee Experience,” it is likely that individuals may concentrate upon certain historical events. For many of us in healthcare and human services, we are painfully aware of the tragic USPHS syphilis study perpetrated on the poor men of the Tuskegee area. Some of us may also be aware of other aspects about the local area and its long history. Certainly, we know of the founding of the Tuskegee Institute (now University) and its immense importance in the development of the Historically Black Colleges and Universities in the United States. Indeed, for many of us, we can concentrate on one or another aspect of the Tuskegee Experience over the decades and centuries.

However, it can be asked if all that is important are historical facts and our reaction to them. I would suggest not. In fact, when one begins to amass the untold historical treasures about the Tuskegee Experience, one swiftly comes to realize that you never really just visit its history or even its geography if you get the chance to travel there. Rather, one enters into the Tuskegee Experience as a type of living metaphor. When one visits the Tuskegee Experience and/or its actual location, you very quickly get drawn up into something much larger than just two dimensional facts and figures.

It is in this light that the J. Todd Moye’s work, Freedom Flyers -The Tuskegee Airmen of World War II, is more than just a book. It truly is a doorway into an experience of learning what it means to serve one’s nation and to oppose every form of human prejudice and discrimination.

Published in 2010 this text focuses on the first generation of Tuskegee Airmen. It is this legacy of fighting for freedom for all that was evident in the reactivation of the 332nd as it became the expeditionary wing that supported the coalition force that liberated Iraq. For me as an Air Force Officer, it is a humbling honor to submit this review on behalf of those men and women who became the next generation of Tuskegee Airmen.

Brief Summary

In this work, the civil rights historian, Dr. J. Todd Moye, captures his experience as the director of the Oral History Project through the support of the U.S. National Park Service as it created a National Historic Site at Moton Field, Alabama. Moye’s work gives multiple first-hand accounts and anecdotes that bring to vivid color the horrific inhumanity of Jim Crow on the lives of African Americans during a time when our nation fought against extreme racism.

This work is built upon over 800 powerfully insightful oral history interviews. These recorded and transcribed interviews provide rich portraits of the courageous individuals who subsequently became pilots, mechanics, instructors, support personnel, and, more importantly, leaders. These oral histories invite the reader into the crucible known as Tuskegee; and make one well aware of the foreshadowed social justice conflicts that followed in the tumultuous decades after World War II.

The story begins with understanding the influence of how a little known research paper produced at the Army War College heavily influenced the preconceived notion of the suitability of Negro personnel power. On the opposite side was the emerging influence of the mass media, black newspaper industry, and the NAACP, which gained political sway over the presidential elections during the war years. Initially, to gain support from the African American communities, despite the objection of senior military leaders, the Army Air Corps became the experiment to demonstrate that African American men could be taught to fly the most complex weapon in the total war environment of that time, the fighter aircraft. There were many that were hoping that this experiment would fail and put to rest the desire to use the military as an agent of societal reform through integration. As we know, their prejudice and anti-intellectual postures failed completely.

Thousands of young men and women came to the deep, segregated South of Tuskegee, Alabama to form a community. Through the experiences and ever increasing need for combat pilots, the text makes it apparent that to continue “separate but equal” training facilities was costly, inefficient and, most importantly, completely contradictory to the nation’s defense and ideals of freedom and justice for all.

Once in combat, these brave souls demonstrated a maturity and courage not seen within the white fighter pilot community of that time. To them the mission was to ensure that the bomber forces got through, but more importantly that those forces returned to their bases intact. For the battle data were evident. If you shot down an enemy fighter, they lost one aircrew member; if they shot down a bomber we lost a crew of ten and the future ability to destroy their means of sustaining a war effort. The initial report of the Red Tails first combat support mission entirely missed this critical focus: it was not about shooting down enemy fighters, it was about ensuring the mission of the bombers! Throughout the training of the pilots as well as the maintenance crew members, the text eminently brings to the fore of one’s realization the indefatigable honored character of the individuals who would learn how to soar, not as individuals, but as a team.

Referred to as the Experiment, in the simplest terms there were those who wondered if these men could form an effective self-sustaining combat unit. In the long run historically, as we know, it would take nearly three score and one year to conclude the social experiment of an integrated air combat unit when the 332nd Air Expeditionary Wing was reactivated during Operation Iraqi Freedom.

Reflection

In the end, the creation of the Tuskegee Army Air Field became the crucible for instilling those men and women with the moral courage and strength to extinguish the oppression of Jim Crow. This text should be a must read for students of history, practitioners in the art of leadership and those who craft policy that ensure our life, liberty and the pursuit of happiness. All citizens that strive for the equality our founding fathers illuminated should read this amazing work. In the personal trials and tribulations of these courageous Tuskegee Airmen we learn with an unprecedented depth what it means to hold the deepest possible commitment to our American ideal that “All are created equal.”
Reviews

When read in tandem with the Federalist Papers and Anti-Federalist Papers and reflecting during this time of the 150th anniversary of our own Civil War, Moye’s text opens us to a powerful humanist perspective on the suffering that is experienced by the disenfranchised of many in our nation. This is a critically important opportunity with the strongest possible significance. In our day and age, there are untold areas where so many suffer and are denied their rights. Sometimes, it is too possible so forget that social injustice and serious violations of human rights occur in our world daily. This text invites us to enter into the broadest possible richness and courage that is The Tuskegee Experience --- a living legacy that brings our own values and sense of self to a healthy and needed moment of critical self reflection.

We owe it to all citizens of this nation to remember those who have fought and who have persevered to make this a nation of the people, by the people and FOR the people. All communities should dedicate time and resources to this fundamental civic duty. This text is an extraordinary moment for us as citizens to remember the past in a way that calls us to be committed anew to building a world that truly makes Freedom Fly!

Film Review

The Invisible War
(2012)

Docuramafilms Cinedigm Entertainment Group
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Author Note

This article is a review of a contemporary documentary film. The film deals with issues of violence in our society today, especially sexual assault and rape. It is a stark and boldly honest work. The viewer needs to be aware of the film's honesty. The documentary is used today for the education, training and formation of the members of today's United States military so as to prevent these crimes from happening again anytime, anywhere. Its message, however, is not only for members of the Armed Forces. Its message applies to us all. This review is offered to help us understand the issues behind this documentary and to apply its message throughout today's societies across the globe. The Invisible War is, from a most thoughtful and powerful perspective, about another area of our world that is in need today of social justice and healing. It is therefore a fitting special feature for these Proceedings of the 2013 Public Health Ethics Intensive. The opinions in this article are those of the author and do not represent the views of the agencies the author has assisted or currently serves.

Introduction and Background

The stage was set perfectly for change in 1945. War was raging on every front and America's military was being depleted by the loss of its sons on the battlefield. Grandparents and extended family members were augmenting the traditional two-parent home. Homemakers, at that time predominantly women, supported the war efforts by working also in factories and mills which produced weapons of war and munitions. Because it was common knowledge that our military was united in its defense against aggression on all fronts, the collaborative efforts of men and women to support the war were done without an afterthought. In 1946, we saw the first introduction of the Women's Army Corps in the legislation proposed by the Eisenhower administration. In June of 1948, President Truman signed the Women's Army Corps Integration Act into law, where women no longer served in support of their male counterparts but rather as equals.

Against, this historical backdrop, the film that is the subject of this review, The Invisible War, has a unique and disturbing power. It is directed by Kirby Dick, who is no
stranger to controversy in his investigation of political circles. Executive producer Regina Kulik Scully, whose organization is well known for healing and educational projects, flanked him.

*The Invisible War* unveils a conflict that many have been forced to deal with despite the persona of equality, which competes with what some may judge as outdated values and beliefs. It is a powerful and disturbing documentary about sexual assault and violence committed on women and men in the military. The victims that came forward in this film are just like you and me, ordinary people who overcame extraordinary circumstances to tell the truth. It is difficult to believe that within the confines of our sacred institutions, safe havens are difficult to find from the grasp of predators who roam freely and often unabated. *The Invisible War* should challenge our thoughts and hearts. Many viewers will experience guilt when viewing what has been perpetrated on the innocent. However, the underlying guilt is not just about any specific act of aggression. Perhaps the deeper guilt is aimed at the failure of others to act aggressively to prevent an act of aggression in the first place.

*The Invisible War* is not an unseen war. It is glaring and reaches beyond the audience for which it was intended. The silence has been broken. The challenge and implications are clear: to bring about substantive and lasting healing; and to ensure that no one ever again is wounded. The challenge is, however, not just within one institution. It is our challenge together as a nation and a global society.

**Film Summary**

In their work, *The Invisible War*, Kirby Dick and Amy Ziering unveil the tragedy of a situation that has become rightfully center stage in the conscience of America: the problem of sexual assault and rape in the United States Armed Forces. In the stories told by actual victims, the documentary reveals a hypocrisy that has been masked by years of false tradition, ideology and injustice that have loomed so tragically in the darkest places in the military. To listen to the stories of each victim, one becomes saddened by the injuries they have incurred, and by the dark shadow that has been cast on one of the world's greatest organizations.

The film begins with the inspiring recounts of the victims addressing why they wanted to join the military. You are inspired as you hear why they may have joined the Armed Forces and the prestige to which each service member aspired. This comes to a frightening halt when one victim states how her life changed when she was raped. For just a brief moment you sit thoughtless asking the logical question that most would:

“How could this happen in one of the most powerful institutions in the world?” As the documentary unfolds, the wounds of those who have been tasked to protect our country start to be revealed. Sexual assault, when it occurs, is no respecter of persons. It does not know race, gender or creed. It devastates its victims, as well as their family members as a result of collateral damage. There is a sense of betrayal that has befallen the victims in this documentary. This betrayal emerges as a common denominator as they reveal their invisible wounds. As a listener, you become captivated by the zeal of the individuals who wanted to join the various branches of the Armed Forces, to serve and protect their country. This zeal becomes transmogrified to anxiety, shame, fear, and in some cases the search for relief through death. One can well ask: How was this at all possible?

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As philosophy and the social sciences teach us, the Zeitgeist is the intellectual way of thinking and being that undergirds and expresses a culture's self-understanding. We learn much about societies, cultures and institutions by observing their behavioral histories and sense among the data the Zeitgeist within. In some, we sense a spirit of inequality or power. Sometimes the Zeitgeist of a particular culture is captured by certain periods of time. In closed societies such as the United States military, however, some of these ideologies transcend generations. In the case of *The Invisible War*, we sense a Zeitgeist that allowed the victimization of the most vulnerable.

As we listen and watch with compassionate care, the victims in this film relate their experience: from personal strength, to deception, to bravery in the face of violation, and then to some form of vindication. When we look behind the curtains in the documentary, one is struck by a culture of secrecy and, in some cases, by blatant cruelty when justice was not readily sought.

The healing in the documentary is two-fold. In the first, the victims get a chance to tell their side of the story, to gain strength and start their healing with, hopefully, a reduced level of shame. Someone finally listens and starts to understand what happened to them. Secondly, the documentary offers the American nation and the United States military a chance to heal, through purging old ideologies that no longer fit with the 21st century military or the general populous. In addition, the documentary reveals the age-old wisdom about the experience of healing itself namely, to have others believe your story, understand your shame, your hurt, and your betrayal may be healing in and of itself.

The horrors that *The Invisible War* reveals to us are not only a “black eye” for the military, but a veil of shame for society at large. It would be remiss not to mention that these are not the first times that sexual violation of an individual has gone unchallenged, where justice has not been sought. In many cases of assault in many spheres of human life, the victim has not been believed, and the evidence pertaining to their case is minimized or lost. This raises a question: How can a victim of sexual assault know vindication, healing or safety, when there is a system that has historically minimized the impact of sexual assault itself?

The documentary’s very title, *The Invisible War*, exemplifies what happens to a victim after they have been sexually violated. There is a veil of shame, guilt and horror that engulfs the victim and causes them theoretically to disappear, only to be left standing alone crying for help. Sadly these cries have for the most part been ignored. As we have come to know, the problem of sexual assault and rape in our society has, in general, continued to mount. In 2011, there was a 30% increase of sexual assault just in the military, the majority of which were female victims who were in their military prime (ages 18-31).

The criminal acts perpetrated against these victims cast doubt on the words of honor, courage, bravery and respect that have been the arteries for the military body throughout the vistas of time. When the body's immune system attacks itself, it is a sign of a grave illness, which, if not corrected, assures certain death. The institution of the military is one of the most esteemed organizations with which one can be affiliated. Like any physical body, infection is repelled by the immune system to ensure survival. *The Invisible War*
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provides us with an x-ray of the internal workings of our greater society. The military, as you see in this documentary, is made up of women and men from the fabric of our nation. But the tragedies revealed in *The Invisible War* not only plague the military. They plague society at large; and that is where the healing needs to start.

**Reflections: Healing as a Nation**

To conceptualize the tragedies which one sees in *The Invisible War*, we must assume that these violations expand beyond the gates of the military. Healing is needed for the victims we see in the documentary. However, that healing is also needed for us as a nation. The victims that came forward in this documentary are representative of a larger group of individuals who struggle in their own Invisible War. These are the individuals who suffer assault and violence and whose voices continue to echo in the halls of forgetfulness and disregard. There must be a national effort to stop the “Invisible War” from becoming pandemic and destroying the soul of our nation. The healing process is more than just philosophical in nature. It must occur through unquestioned personal, institutional and societal commitments of relinquishing perceived power, practicing collective accountability, and removing emotional anchors that keep us from seeing the truth.

In a sexual assault, the root issue is a power differential between the perpetrator and the victim. Though this is common knowledge, it is the perceived power differential that has plagued the majority of our personal encounters. Power more often than not is not given but taken due to false assumptions, cultural backgrounds and/or societal norms. In some cases when power is issued, it can be abused. Such is the case of the stories in this documentary. Removing this power differential would be a paradigm shift for our nation. Especially in a day when we are quick to say we have a society that is supposedly equality-based, this paradigm shift should be essential. What would it look like to treat, view and interact with another truly as an equal? As strange as this may sound, seeing each other without the presence of a power differential would be an odd occurrence. Thus the likelihood of harming another individual would be greatly reduced due to accountability.

There is an ownership that comes with accountability. We start to invest in the wellbeing of another. Yet accountability can only be effective when it is done collectively. As we saw in *The Invisible War*, the lack of accountability tarnished our nation's greatest institution. It is our collective accountability that fosters an atmosphere of equality, allegiance and respect. These basic ideas are not foreign to most. However, they become dismantled when levels of power lead us to a position where we do not hold each other individually or collectively accountable for nefarious behavior.

The human animal knows that in our societies, cultures and nations the role of perpetrator and/or victim has touched deeply our experience over time and space. This is as true of America as well as its institutions. *The Invisible War* shows how this experience has touched our Armed Forces. If true healing is to occur, then it is critical that the perpetration of such crimes and the victimization of the powerless come to an absolute end. Unfortunately, what keeps the healing from happening is the clinging of individuals and institutions to emotional anchors that keep one from accepting the problem in the first place.

Emotional anchors come in many forms. They have bound individuals to false beliefs, principals and practices due to one’s inability to break free. Clinging to our emotional anchors is not an uncommon experience. It is part of being human and part of being members of specific cultures. Yet unless we unclench our hands from around emotional anchors of apathy and denial, we cannot see the truth about who we are and what we do. Once we as a nation and as individuals let go of our emotional anchors, we can more truly become accountable to each other and ourselves. Then self-reflection gives birth to healing, allowing us to let go of that which has held us back. We also need to remember that being emotionally anchored is not only common for the victim, but also the perpetrator. Being free means releasing weight. It means letting go.

Relinquishing perceived power is the gateway to collective accountability. Our nation's morality is at stake. *The Invisible War* makes that eminently clear. Yet the power of the documentary is not just for our nation and our military. It is also for each of us. For in the history of our nation and the world, we see time and time again the oppression of the poor, the downtrodden, and those the majority would like to judge as different and therefore less than. It is time we let go of our emotional anchors and ascend to the summit of healing. It is time for us to set the anchored free and know the freedom of real healing.
**Reviews**

**Film Review**

**The Unobtrusive Subversive:**

**Reflections on the 2012 Documentary, Ethel**

**A Film by Rory Kennedy:**

**The Personal, Untold Story of Ethel Kennedy**

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**Author Note**

This article is a film review of a contemporary documentary. It serves as a special reflection upon the theme of the 2013 Public Health Ethics Intensive and the scholarship that resulted from the course. This review is offered to help us continue our commitment to social justice and human rights wherever human dignity is denied across the globe today. The opinions in this article are those of the author and do not represent the views of the agencies the author has assisted or currently serves.

**Introduction**

In 2012, Rory Kennedy produced and directed a special documentary shown on HBO and which was premiered at that year's Sundance Film Festival. Rory Kennedy was the last of the children born to Robert and Ethel Kennedy. She was born the December following her father's tragic assassination in June of 1968. From the moment the documentary opens, you are drawn into the power of a family whose individual members always were on the cusp of some moment of transformation. From Ms. Kennedy's interviews with her mother and other family members, to sharp clippings from the family's 1960's life, one always sees each member on the move. This is particularly true of Ethel Kennedy and very true in various moments of Robert Kennedy's life as he moved from being a lawyer and politician to being a man caught up in civil and human rights.

In learning about the 2013 Public Health Ethics Intensive and its materials, the images of transformation caught my eye. This experience deepened for me as I reflected on the theme of the course namely, "From A Dream to a Vision: An Ethical Journey." These same images of transformation came back to me in powerful ways while reviewing the film, *Ethel*. Yes, something most curious was raised up inside me, especially as I reflected how Ethel Kennedy's powerful presence was seemingly behind the scenes. Realizing this, a few uncommon terms came to mind that reflect what I believe is one way to capture the energies of Ethel Kennedy and this entire film for those who work in our world for social justice as an ethical journey.

One particular phrase came strongly to mind for me, namely a person who is an unobtrusive subversive. The online dictionary interprets the word “unobtrusive” as an adjective meaning not conspicuous or attracting attention. Equally the dictionary articulates “subversive” as either an adjective: seeking or intended to subvert an established system or institution; or a noun: a subversive person.

When one views *Ethel*, one almost immediately gets the image of Mrs. Kennedy as one who behind the scenes was the source of the family's energies. She subverted any tendency in any of the children to think only of their own selves. She and her husband did everything to make sure that they became other-oriented. And she carried this life stance over into all of her own life's activities then and now. Yet for what general goal might we imagine did she expend her energies so selflessly? That seems to be bound up in another grouping of words that find their origin in the Greek term, *koinonia*.

*Koinonia* is often translated from the Greek as conveying the experience of community. Like other foreign language terms, it has a multitude of deep meanings that no single English word can adequately express. *Koinonia* also signifies a moving sense of goodness; both an inner goodness toward virtue, and an outer goodness toward social relationships. It conveys a sense of bondedness with others. It points toward the experience of human nature as an experience of mutuality, and mutual or communal undertakings. Its variations appear in related Greek terms such as koinonos, meaning to share, or to be in a relationship; and koinonein, meaning to have something in common.

As we see in the film, Ethel Kennedy embodied and embraced all of these qualities and descriptions. She was unobtrusive. Yet she was also a woman embodying a positive sense of subversion who, like her husband, sought to promote change from the bottom up. And she did this for the sake of her family's sense of community as well as to promote the goodness of every human person and every human community. In *Ethel*, Mrs. Kennedy is the Unobtrusive Subversive who, in her own way, built human community among all those she met in her public and private life.

It could be stated that history distinguishes Ethel Kennedy simply because she was the wife of Robert F. Kennedy. Perhaps at times this distinction might be argued as her being always in his shadow. Some might think this to be especially true when she is compared with her contemporay Jacqueline Kennedy who was better known and generally regarded as more in the social spotlight. However, the film clearly portrays that Mrs. Ethel Kennedy, though demure, was never and is no shrinking violet. A mischievous streak paired with determination, wit, guile, and compassion all reveal a strong and resilient character from her formative years onward. She conveyed these same tenets during her marriage, and imparted as well as demonstrated these principles to her children, previous to, during and after the assassination of her husband.

This documentary is a powerfully effective and very frank portrayal of Mrs. Kennedy's life. It chronicles her birth, early childhood, high school and collegiate years as well as her marriage to Robert Kennedy. It reveals to us how she contended with his death and continues to advance the Kennedy Legacy as a legacy aimed at improving the lives of women, men and children all across the world — especially those who are poor, dispossessed, abandoned, and underserved.
Summary Points

The Formative Years: Learning the Ethos of Community

Ethel Kennedy was born Ethel Skakel in Chicago, Illinois, on April 11, 1928 to parents George and Ann Skakel. She was one of six children. Ethel's mother was a fervent Catholic. Initially her father worked as a railroad clerk, earning a modest salary. Eventually, he, alongside a few of his co-workers, built a small coal and coke business into an expanded enterprise titled, The Great Lakes Coal & Coke Co. The business ultimately converted to the named Great Lakes Carbon Corporation. Consequently, the Skakels became tremendously prosperous; and, in 1934, when Ethel was five years old, the family settled in Greenwich, Connecticut.

It is quite apparent throughout the film, that though the family became very wealthy, a strict Catholic upbringing ensured that many associated deep values were imbued in her and her brothers and sisters. Accordingly, throughout the film, we see how Mrs. Kennedy inspired these same ideals in her children. What had been the gift of one generation she made sure to pass on to the next. Though Mrs. Kennedy was instilled with such a staunch religious upbringing, this did not dampen her mischievous as well as competitive streak. After high school, she attended the elite Manhattanville College of the Sacred Heart, which she befriended and roomed with Jean Kennedy of Massachusetts.

Marriage to Robert Kennedy: Community and Otherness

In 1945, then Ethel Skakel went on a ski trip with Jean Kennedy and became acquainted with Jean's brother, Robert. Robert was dating Ethel's sister at the time; however that relationship soon ended. Ethel and Robert soon were together. Later that year she helped Robert with his brother John's congressional campaign. An inseparable bond had been forged between Ethel and Robert, and the two married in 1950, a year after she graduated from Manhattanville College.

Shortly after, they moved to Charlottesville, Virginia, where Bobby Kennedy attended the University of Virginia Law School. Their first child, Kathleen, arrived on July 4, 1951. Joseph II would come the next year, followed by their third child, Robert, in 1954. In total the Kennedys had eleven children. Subsequently the family relocated to Washington D.C. as Robert began to work for the Department of Justice.

Though not expressly stated in the film but woven into its message, we can see with a high degree of certainty that Mr. and Mrs. Kennedy worked most closely in tandem as a team. Mrs. Kennedy aptly led the affairs of the home. This allowed Mr. Kennedy to center on his professional life. In 1953 he was appointed by Senator Joe McCarthy to be the Assistant Counsel of the U.S. Senate Permanent Subcommittee on Investigations, in which he later resigned and then subsequently returned to the Senate Committee Staff as chief counsel for the Democratic minority in 1957. This same sense of family community and teamwork allowed Bobby Kennedy the time to engage in his political pursuits. In 1952 he managed his brother John's successful senatorial campaign; then in 1953 Bobby joined the Hoover Commission.

As this documentary clearly portrays, Ethel Kennedy was integral in the impregnation of the civil rights ideology in her children. She imparted this message to the children via letters from their father thus instilling in them the values of justice and dignity for all. One such letter from Bobby Kennedy to his children expressed the hope that the racial discrimination of the times would be gone by the time they attended college. This particular letter, very thoughtfully presented in one of the scenes of the film, was written in response to the tragic denial at that time of the right of black women and men to matriculate at monolithic southern institutions such as Ole Miss and University of Alabama. This scene, along with many others, showed how deeply Ethel and Bobby Kennedy sought to inculcate in their children that any form of abject discrimination was wrong; and that they as citizens had a moral responsibility to engage and fight whenever and wherever it was encountered.

Family and National Tragedy: Deepening the Experience of Community

Mrs. Kennedy endured numerous tragedies in her lifetime. Three were obviously central in the film. First she had to contend with the death of her parents in a plane accident. Then there was that fateful day of November 22, 1963, the assassination of President Kennedy. Finally and most tragically for Mrs. Kennedy herself, there was her beloved husband Bobby's assassination in 1968.

As one sees so well in the film, in each instance Mrs. Kennedy exhibited an unobtrusive stoicism and a quiet, loving fortitude. She subverted any possible meltdown in herself and others. Even in the face of such tragedies, she continued to instill in others the fullness of what was presented above as "koinonia," namely human community. At her parents’ untimely death, she dealt most effectively with her grief and pain. She centered herself on her nascent family for support. She even used the tragedies of the moment as raw energies to strengthen her endeavors in family political campaigns. After the assassination of President Kennedy, via his role as the attorney general, was fighting for the civil rights of all citizens, Mrs. Kennedy made sure to impart the historical significance and importance of those civil rights battles with her growing family.
President Kennedy, she was the dutiful, considerate, yet enduring partner. She knew well and engaged the tumult, disconsolation, and the seemingly incontestable bereavement exhibited by her husband. As she loved him and supported him, she did so as the ultimate expression of their primordial bond of community with one another. As the documentary vividly portrays, she afforded him the solitude he needed to process his melancholy and emotions.

As we see in the film, following his solitude over his brother John's tragic assassination, Bobby Kennedy had a renewed vigor to fight against injustice. Mrs. Kennedy was not only by his side in their ever-deepening love, but also actively engaged in this fight with him. Along with him, she worked vigorously to subvert the problem of injustice and discrimination. This was very evident in the film in her reflections on Mr. Kennedy's extreme disconsolation after visiting the poor black children of the Mississippi Delta. She recounted how deeply distressed he was at the children's poverty. This was equally very evident in the film in her reflections on Mr. Kennedy's eventual friendship and kinship with activist Cesar Chavez. On that, she reflected that her husband and Cesar Chavez were kindred spirits on a quest for equality, a quest that she herself unobtrusively but definitively co-signed and engaged.

Obviously, the film captured with great sensitivity the assassination of Bobby Kennedy in 1968. Mrs. Kennedy had to be strong not only for herself but also her eleven children. Again she displayed that unswerving stoicism and fortitude that was inculcated in her from childhood. In that moment of most intense pain and confusion, Ethel Kennedy's personal character formation was visible. Its portrayal in the film is deeply moving. In fact, even for the most ordinary viewer who may not be aware of the fullness of the Kennedy Legacy, Ethel Kennedy embodied in herself an indefatigable commitment to otherness. As we see in the film in many touching ways, she then and still today continues to sustain, advance and promote the efforts and legacy of her husband and the Kennedy family. And that legacy is clearly to human rights and social justice. It is a legacy about ethics itself --- about ethos, namely the fundamental character of the human person. Hence at the end of this moving documentary, one might wonder if it is really over. Is any legacy ever finished?

Conclusion

A number of years ago, a good friend shared with me a scholarly work about mythologies and folk tales. If I remember correctly, he said that one of the powerful lines out of this work was “Any dream worth remembering takes a long time to understand.” That saying came back to me after I finished watching Ethel. Like any good book or good film, one gets drawn into it. That certainly was the case with Rory Kennedy's work on her mother. In some ways, when one watches Ethel you sometimes feel as if you are looking into a mirror and asking what is its significance for one's own self. In fact, Ethel is a type of dream that requires a long time, even a lifetime, to understand.

As a film, Ethel chronicles only some of the selective moments of Mrs. Kennedy's and her family's history. Unfortunately, there are some cynics who may criticize and choose to view the film as a revisionist spinning of history in order to regale ancestral legacy. That perspective is parochial and completely unworthy. It completely misses the point of any good film let alone this documentary.

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Instead, Ethel is a documentary showcasing a public figure who was remarkably private and unassuming in many ways. The documentary chronicled the partnership she shared with her husband and the relationship she had and still has with her children. Yet even more deeply than these, the film powerfully details how one woman's seemingly quiet building of family and social activities was far from silent. Unobtrusive as Ethel Kennedy may have been, she indeed “from the bottom up” built family values and strong relationships and political activities that were extremely powerful. She subverted in all those around her any tendency toward selfishness, greed, and self-preoccupation. The film clearly portrays her as one who lived for the benefit of others and carried that over into any and every opportunity to advance the causes of civil rights, social justice, human dignity and human rights across the globe. With all of this in mind, she clearly participated in the shaping of her children and the historical tapestry of the United States.

But what of us? What does this documentary seek to “document” in our own selves? How can we remember this film and take the long time it needs to understand and live out its meaning for us and for others?

As already noted, the theme for the 2013 Public Health Ethics Intensive was “From A Dream to a Vision: An Ethical Journey.” In her own time, Ethel Kennedy knew the Dream for Justice and Peace. She made it even more than just a vision. She made it a reality in her own journey and in the journey of her family and all those around her. For us, as we take the long time to understand this powerful documentary so skillfully produced and directed by her daughter Rory, we need to look deep within ourselves and just as deeply into the issues of our own times.

All of us, like Ethel Kennedy, have known our own pain. We all have suffered. Some, even whole communities, have suffered horrifyingly. This is the human experience. Sometimes the pain and suffering make our dream into a nightmare. Yet at the same time as any of us are on the road to healing, we have the strong figure of an Ethel Kennedy to remind us of something critically important. As we tend our own needs, our needs can and must become an energy that catapults us outward from our selves so as to meet the needs of all children, women and men who suffer in this life especially at the hands of human hate, greed, prejudice, and power. As the April 2013 course experience and materials indicate so well, the dream of social justice has to become more than just a dream. It has to become the vision before our eyes. Above all, it has to become a reality. And it can only become a reality if we are as brave as an Ethel Kennedy to take the first steps, however unobtrusive and seemingly quiet, out of our own selves and enter into a journey of true subversion in our modern world --- the journey that is the service of others.
Please join us for the 2015 Commemoration Events & Public Health Ethics Intensive

Monday, March 23rd to Friday, March 27th