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Preface

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Julian Armand Cook, MDIV is the Senior Pastor of the historic St. Mark Congregational Church, United Church of Christ of Boston, MA. Founded in 1895, St. Mark is the city’s oldest Black Congregational Church. In May of 2016, Reverend Cook graduated with a Masters of Divinity (magna cum laude) from Boston University (BU) School of Theology, where he was awarded a full scholarship as a Dean’s Fellow and Mary McLeod Bethune Scholar. While a student, he served as Research Assistant and Teaching Fellow to Dr. Walter Earl Fluker, a renowned social ethicist and scholar on the lives of Dr. Martin Luther King, Jr. and Howard Thurman. As Dr. Fluker’s assistant, Cook aided in the completion of three major works: Volumes 4 and 5 of the Papers of Howard Washington Thurman and The Ground is Shifting: The Future of the Black Church in Post-Racial America. Most recently, Cook was appointed Assistant Director of Thurman Networks at Boston University’s Howard Thurman Center for Common Ground - a student center committed to promoting Thurman’s principles of the “search for common ground” and the “unity of all people.”

Caroline Deloris Fermin, BFA graduated from New Orleans Center for the Creative Arts and later the Juilliard School in New York City with a BFA in dance. Caroline has performed for ballet and modern companies including James Sewell Ballet, Chamber Dance Project, Sidra Bell, and Adam Weinert. She is a founding member of Gallim Dance where she danced professionally both in the US and abroad. There she spearheaded Gallim’s education program and served as Education Chair, teaching workshops and master classes across the country. Caroline is a choreographer, specializing in collaboration, most recently working with the actors
Ajeenah Haynes, MA, MPH, PhD is a lecturer at New York Medical College in the Department of Epidemiology and Community Health and is a member of the Delta Omega National Honorary Society in Public Health. She also currently assists in the management of the Research and Evaluation Department of Clifford Beers Clinic, a community-based mental health clinic that provides trauma-informed interventions and care coordination for youth and families. Dr. Haynes earned her Ph.D. in Medical Sociology from Howard University and her MPH, with honors, from New York Medical College. Dr. Haynes is a trained survey researcher and cognitive interviewer. She has expertise in item development and semi-structured cognitive interviewing in the areas of post-traumatic stress disorder and health behavior change. She is also trained in qualitative data analyses. As a medical sociologist and public health professional, her work focuses on the ecological approach to community health and healing. She also addresses health disparities and safety of vulnerable worker groups and social justice. Her areas of interest are the social construction of illness, illness behavior, and decision-making processes when ill. She focuses on vulnerable worker groups in terms of health disparities and safety; and is particularly interested in occupation-related psychosocial stress.

Cesar Danilo Fermin, BS, MS, PhD was born in the Dominican Republic where he obtained a BS at UNPHU in Science-Education. He studied English at Florida Institute of Technology where he also earned an MS in Cell Biology and a PhD in cellular and Molecular Biology completing a post-doctoral fellowship in Pathology of balance at Baylor College of Medicine in Houston, Texas where he served as Assistant Professor. He moved to, and was tenured at Tulane Medical School. He moved to Tuskegee University (TU) as Associate Dean in the College of Vet. Med. Nursing Allied Health, as Graduate Studies Research Dean, and since 2014 serves as Provost VP for Academic Affairs. He is a tenured professor of Biology. Known internationally for high-resolution transmission-electron-microscopy of nature’s nanoparticles (otoconia biological crystals) a skill that he applied to an extensive list of publications with viruses, through work funded by the National Institute of Health, NASA, etc. Dr. Fermin has a broad background/knowledge of biological systems, neural plasticity, and pathology. His scientific acumen includes 4 decades of research reported in hundreds of publications, book chapters, and proceedings, plus developing a thorough understanding of issues in this paper that are not difficult to resolve if only equitable initiatives were to drive health care delivery. The content of the article published here is the results of over 5 decades following literature about the human body resilience, capacity to repair, and amazing power of alternative healing methods used elsewhere but discarded in western medicine.

Crystal M. James, JD, MPH was born in Brookton, Georgia. Attorney James received her Bachelor of Science degree from Clark Atlanta University, her Master of Public Health from Rollin’s School of Public Health at Emory University, her Juris Doctorate from University of Houston, and her license to practice law from the State of Georgia, all by the age of twenty-six. She has been able to not only work within her science and public health interests, she also maintained a successful legal practice that focuses mainly on the areas of civil right issues, which include labor and employment issues, criminal law, personal injury, as well as domestic relations for fifteen years. In 2011, Attorney James also founded Chrysalis International Consulting, LLC a consulting firm whose mission is to establish and sustain a cadre of professional consultants that provide excellent services in the fields of public health, statistical analysis, data management, program planning, educational development, and program evaluation. Attorney James has been lecturing as adjunct faculty and guest lecturer in Public Health since 1998 at Morehouse College and at Morehouse School of Medicine’s Public Health Program since 2001. As President and CEO, James has over seventeen years of public health experience and extensive background in program planning and evaluation that she brings to her new role as Associate Professor in the Graduate Program of Public Health in the Department of Pathobiology at Tuskegee University. Crystal James is also a mother and proud member of Delta Sigma Theta Sorority, Incorporated.

Lillie Jewel Tyson Head, BS, M. Ed., Ed. S is the daughter of Freddie Lee Tyson, one of the African American men victimized by the United States Public Health Service Syphilis Study (USPHS) at Tuskegee and Macon County, Alabama from 1932 – 1972, and the daughter of Johnnie Mae Neal Tyson. She and her husband Wilbert are the parents of two sons, Wil, Mark (wife Tanikia), daughter Carmen, and the grandparents of Bryce, Kylie, and Trinity. Mrs. Head is the Chair of Voices for Our Fathers Legacy Foundation, (VFOFLF) a nonprofit organization founded by descendants in 2014 “To uplift the legacy of the USPHS Syphilis Study by honoring the 623 men in the study, convening their families to preserve history and enrich education in clinical and public health research.” Under her leadership, the VFOFLF is working closely with the National Center for Bioethics in Research and Health Care at Tuskegee University to tell the untold stories of “Their Fathers and Mothers.” She is a weekly volunteer at Booker T Washington National Monument in Hardy, Virginia, where Booker T Washington was born enslaved and freed. Mrs. Head is a member of the Monument’s Living History Guild reenactment program. She retired as a Physical Education teacher and Educational Consultant after 33 years from the Waterbury Public School System, Connecticut Area Cooperative Educational Services, and Connecticut Capitol Region Educational Council. Mrs. Head is a Graduate of the historic Tuskegee Institute, Southern Connecticut University and University of Bridgeport in Connecticut.
Ralph V. Katz, BS, DMD, MPH, PhD, FACE is Professor and former and founding Chair, Department of Epidemiology & Health Promotion, NYU College of Dentistry, a proud graduate of Tufts University School of Dental Medicine (Class of ’69) and subsequently an epidemiologist who has focused on the study of oral diseases and of health disparities. He has been a Fellow of the American College of Epidemiology (F.A.C.E.) since 1982. He currently annually teaches “the ethics and politics” of public health to international baccalaureate college students at the NYU Abu Dhabi campus in the UAE. He has served as the Director of the NIH-funded NYU Oral Epidemiology Postdoctoral T32 Training Program for 20 years. He has led the Tuskegee Legacy Project research study team for the past 20 years, since its inception in 1997. He served as the Director of two NIH-funded oral health research centers focused on health disparities and minority health for the better part of two decades, between 1992-2009. Having served on the National Legacy Committee which initiated the formal request for a Presidential apology, he was an invitee to the White House by President Clinton for the May 1997 Presidential Apology for the Tuskegee Syphilis Study. He currently is a Visiting Scholar and a member on the External Board of Advisors at the National Center for Bioethics in Research and Healthcare at Tuskegee University, which was formed by order of President Clinton in his Presidential Apology.

Velma E. Love, MDiv, PhD is an independent humanities scholar, an author, executive coach, trainer, and wellness advocate. She is Co-Founder of the Lee Thompson Young Foundation for mental health education and awareness, as well as Founder and CEO of Story Catalysts Coaching & Consulting, LLC, where she inspires and guides individuals and organizations in creating new wellness stories to live by. Having a special interest in spirituality and health, Dr. Love is a former visiting scholar and director of “Empowering the Saints: Promising Practices in Black Congregational Life,” a national research project conducted by Howard University School of Divinity. In addition to her work at HUSD, she has also held appointments at Florida A&M University, the Interdenominational Theological Center, and Winthrop University. Dr. Love is an experienced cultural worker who uses storytelling to create community and advance a new human story of wholeness and wellbeing. She holds a Bachelor of Arts in Sociology from the University of South Carolina, a Master’s of Divinity from Union Theological Seminary in New York City, and a PhD in Religious Studies from Claremont Graduate University in Claremont, California.

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Arvilla Payne-Jackson, Ph.D. is a Professor of Anthropology and Linguistics in the Department of Sociology and Anthropology at Howard University. She has a doctorate in Sociolinguistics from the University of Pennsylvania and post-graduate work in Anthropology at Catholic University. She has done extensive research and publication on traditional medical systems in the Caribbean and the United States. She has conducted ethnographic evaluation for federal and non-profit organizations including: The Agency for Children, Youth, and Families; the Center for Substance Abuse Prevention; the Early Head Start Program; the U.S. Department of Health and Human Services and District of Columbia Health Department HIV/AIDS Administration; Department of Labor: Youth Opportunities Initiative: Ethnographic Evaluation of Community Wellness; White House Office of National Drug Control Policy; and Marshall Heights Community Development Organization: Fighting Back Initiative.

Clyde C. Robertson, Ph.D. is an Associate Professor of History at Tuskegee University. He earned a Ph.D., in Africana Studies is from Temple University (1998) and a MA in Mass Communications Theory from Howard University (1982). He is the author of several articles investigating Africana Studies and History, including Administration of Africana Studies at Black Colleges in Africana Studies: A Disciplinary Quest for Both Theory & Method, published by McFarland & Company. He is also investigating the impact Hurricane Katrina is having on African Americans. To this end, Dr. Robertson has authored the article entitled Hurricane Katrina through the Eyes of African American College Students: The Making of a Documentary (Journal of African American History, Volume 93, Number 3, Pgs. 392–401, ASALAH, Washington, D.C., September 2009). Along with Joyce King, Ph.D., he coauthored the article entitled Bon Feerey: A Teaching Methodology for Healing the Wounds of Distance, Displacement, and Loss Caused by Hurricane Katrina (Journal of Black Studies, Volume 37, Number 4, Pgs. 469–481, Sage Publications, Los Angeles, CA, March, 2007). During the summer of 2009, Dr. Robertson completed the Intensive Bioethics Course 35 at Georgetown University in Washington, D.C. In 2010 his book, Africa Rising: Multidisciplinary Discussions on Africana Studies and History, was released by Africa World Press. His most recent article, Bus Ride to Justice: The Life and Work of Fred D. Gray an Essay and Review, was published in The Journal of Healthcare, Science and the Humanities, Volume VI, No. 1, pgs. 147-159, National Center for Bioethics in Research and Healthcare, Tuskegee University 2016.

Edward L. Robinson, Jr, PHD is an Instructor at California State University at Fullerton & Dominguez Hills. He received his doctorate at Claremont Graduate University, Claremont California in Cultural Studies with an emphasis in African American literature, literary theory, culture, and media. His literary projects and scholarship includes work on the African American
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poets Lucy Terry and Phillis Wheatley, Black humanity in early American national literature, and the construction of Gay Masculinities in Black American and Diasporic Literature. Edward is presently preparing to debut his literary blog “The Baldwin Room” and website where he writes about popular culture and new diasporic literature and Black development of Superheroes. He is presently working on his novel The Prince of Dover’s Bluff.

Rafael Sanchez-Cardenas, MD was born in the Dominican Republic where he obtained a MD at Universidad Autónoma de Santo Domingo (UASD) in 1985. He practiced medicine for fifteen years, studied English and in 1992 and later earned a MS in sexual and marital therapy at the Sexual Education Institute APEC (INSAPEC), Santo Domingo, Dominican Republic. He served as a Professor of social and Community Medicine at Universidad Iberoamericana (UNIBE) from 1989-1994. In 2012 he earned a MS in Applied Economy 2012 and began administration. Dr. Sanchez-Cardenas also served as Editor for the digital Newspaper Ojalá do from 2008-2014. He is Vice minister for International Affairs of the Ministry of Higher Education, Science And Technology (MESCyT) in the Dominican Republic government since 2012, through which he has been building partnerships with international universities where Dominican students funded by MESCyT are currently pursuing studies in many fields of science (England, Spain, France, Czech Republic, Canada, Brazil, Cuba, Puerto Rico, Honduras, Colombia), and the US universities and research centers at Tuskegee University, Illinois State University (Urbana), Louisiana State University, and other institutions all over the world. Dr. Sanchez-Cardenas was instrumental guiding the documentation that lead to the current agreement starting Fall 2016 through which graduate students are pursuing MS at Tuskegee University. A second cohort pursuing MS and PhD degrees fully funded by MESCyT will be processed for FA17.

Emmanuel A. Taylor, MSc, DrPH is a Health Scientist Administrator/Program Director in the Immediate Office of the Director (IOD) of the NCI’s Center to Reduce Cancer Health Disparities (CRCHD) since 2004. In this role, Dr. Taylor provides technical and scientific expertise to the evaluation of health disparities research and training programs within the Center. Dr. Taylor has over 30 years of public health related experience at community, State, and Federal levels as well as experience in the private sector and academia. Prior to joining CRCHD, Dr. Taylor was President and CEO of Health Information Management Associates (HIMA), Inc. While at HIMA, Inc., he served as the chief epidemiologist and director of health informatics, research and program evaluation. He was an Associate Professor of Public Health at Morgan State University, and Senior Epidemiologist for Minority Health at the Centers for Disease Control and Prevention (CDC). Dr. Taylor received his doctorate in International Health/Epidemiology from the Tulane University School of Public Health and Tropical Medicine, with a specialty in the application of epidemiological methods for planning and evaluation of public health programs; a M.Sc. in Health Education and Communications, and a B.S. in Pre-med/Biology from the University of Southern Mississippi.
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Message from the Interim Editor

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Since 2010, the National Public Health Ethics Intensive Course (PHEI) has provided an academically and professionally rigorous course for physicians, dentists, nurses, other healthcare professionals and medical residents, graduate students, undergraduate students, university faculty and other leaders including health educators, healthcare administrators, and community advocates. The course addressed historical and contemporary issues through various spheres of ethics. In 2016, the theme of the PHEI was, ‘Healing the Family through Social Justice.’ This edition of the Journal for Healthcare, Science and the Humanities includes several peer reviewed articles from the 2016 course, as well as other articles that also address issues of social justice. Consistent with the approach by the National Center for Bioethics in Research and Health Care, the authors in this edition considered in their writings spheres of ethics through the lens of race/ethnicity, sex/gender and income. In his article entitled, Luminary sheds light on the ‘Legacy’ of the USPHS Syphilis Study at Tuskegee: tracking Arthur Caplan’s comments over the past Quarter-of-a-Century, Ralph Katz DDS, MPH, PhD, reviewed the years of scholarly writings and activism by Arthur Caplan. Dr. Caplan has published over 300 articles, books and book chapters, newspaper paper articles, op-ed and other public writings. He rightly credits Dr. Caplan with sustained contributions to the field of bioethics and ends with a profound statement by Caplan: “[It was] …the revelation of maltreatment of subjects in experiments such as the Tuskegee study [that] produce new laws and regulations regarding the conduct of human experimentation.” According to Dr. Caplan, institutional review boards, commonly referred to as IRBs, were a direct result of the ethics violations committed during the United States Public Health Service Syphilis Study at Tuskegee.

In his article, Health Literacy and Ethical Considerations for Health Equity in the New Public Health Era, Dr. Emanuel Taylor M.Sc., Dr. P.H., responded to Bailus Walker PhD, MPH’s presentation on the importance of health education and health literacy. Walker stated that, “despite advances in literacy and education as well as major improvements in communication…in this period of unprecedented acceleration in the pace of scientific and technological advances, and the educational focus on Science, Technology, Engineering and Mathematics (STEM)…there will still be a great gap between medical (protective) knowledge and the public acceptance of it.” Dr. Taylor’s article is in response to points raised in the keynote presentation by Dr. Bailus Walker. The role/ importance of health education and the challenges faced by health educators in helping address the inequities in the uptake of potentially beneficial...
Interventions for lifestyle changes among various U.S. population groups were highlighted by Walker. Walker illustrated this assertion with a couple of examples: the lack of detectable decline in obesity rates despite clinical and public health efforts aimed at obesity reduction; and, despite widespread smoking cessation programs including legislative interventions, tobacco use is still the underlying leading cause of death in the U.S.” He concluded that, “the endpoint of health education is not just awareness of facts but an emotional conviction toward both attitudinal and behavioral changes. Providing concrete knowledge of health and health-related issues is less important than insight, rousing interest, and nurturing values that can achieve a healthful lifestyle.” Dr. Taylor agrees with Walker, but adds that “the missing link” between health education (action/intervention) and desired behavior change (goal) is the inability of the target audience to fully understand and personalize health information due to limited or lack of “health literacy.” Dr. Taylor is a well-experienced epidemiologist. He agrees with Dr. Walker’s conclusion that the end product of health education efforts should not be merely the raising of awareness of facts about health and/or health-related issues.

Using cultural trauma theory, personal and public narrative, Velma E. Love PhD, examines the concept of family evolution in the context of African American identity formation and its relationship to a social history of racial hierarchy in the United States. Dr. Love explores the various constructs of family including ancestral lineage, communal association, and future generations. She also explored narrative change in service to racial truth, healing, and transformation within the context of the U.S. Public Health Service Syphilis Study at Tuskegee to examine the topic “The Evolution of Family: From Trauma Narrative to Healing Narrative.” Dr. Love uses trauma theory as a framework for her paper and draws attention to Black enslavement as a marker in the formation of an African American identity. She discusses the work of sociologist Ron Eyerman who writes about the direct experience of slavery. She posits that the collective memory of the slave experience is also important and plays a significant role in the making of an African American identity. The out-picturing of that collective memory “provided a mobile narrative that could transcend time and space and could be spoken, painted, sung, danced, written in poetry or prose and serve as a means of building social cohesion and ultimately an African American identity, an identity rooted in an historical, cultural trauma.” Dr. Love expertly describes how the descendant family members of the 623 African American men in the USPHS Syphilis Study who attend the Annual Apology Commemoration events at Tuskegee, come together each year for a ritual of remembrance. This ritual acknowledges and recounts the historical and continual trauma for the descendant family members from the Syphilis Study, but also highlights the movement from a trauma narrative to a healing narrative.

Arvilla Payne Jackson PhD and Ajeenah Haynes PhD, MPH provide an intriguing paper about The Voices for Our Fathers Legacy Foundation (VOFLF), which is a 501c3 organization created by descendant family members of the men who were in the United States Public Health Service Syphilis Study in Tuskegee and the ongoing partnership with The National Center for Bioethics in Research and Health Care at Tuskegee University. They discuss the steadfast partnership between the descendant family members the National Bioethics Center in assuring the true story about the men, what actually happened, and the current and future plans to assure the legacy of the men is corrected and appropriately acknowledged. Drs. Payne Jackson and Hayes emphasize that the impact of the USPHS Syphilis Study extends beyond the abuse of the men who were in the Study, but also includes individual and collective anger, pain, and suffering that continues among the descent family members. They also describe the important notions and various ways family is operationalized, using the Tuskegee Family as an example.

Chukwudi Onwuachi-Saunders, MD, MPH and Adenike Bitto, MD, Dr.P.H., MPH in their article, “Nation to Nation: Family to Family” raise several important questions: Are we asking questions that will shift the paradigm of disproportionate adverse health outcomes for African Americans? They challenge the reader to reframe their language which may allow a different way of thinking and acting. They also focus on identity as a strategy to shift African American thinking from survival toward optimal health and wellness. They challenge clinicians to consider expanded versus traditional definitions of identity and to employ strategies to include expanding client interviews to better understand the context in which people address their health concerns.

Instead of nations, consider communities! Instead of families, consider intimate and committed relationships! These definitions may serve as a more valuable component in relation to assessments and treatment plans. Recognizing individuals’ current community living conditions and social networks plays a critical role in health and wellness. Use of expanded definitions eliminates silos, thus providing a broadened view which will shift the paradigm to optimal health and wellness. Their paper is rooted in social determinates of health and grounded in social justice, as a matter of life or death.

Clyde Roberts PhD writes about, The School as an Extension of Family. He starts by referencing a 1919 protest poem by Harlem Renaissance writer, Claude McKay, to highlight the “combative spirit” of African Americans’ response to oppression and racism. Dr. Roberts writes that they created towns, commercial districts, and institutions which all served as buffers from the scorn of white supremacy. He also writes about Tuskegee University, previously known as Tuskegee Institute, as an example of institution building. Dr. Roberts’ current is on the faculty at Tuskegee University. His article reviews the long history of African Americans striving for educational opportunities as an essential tool for the advancement of the race. Dr. Roberts’ article examines African American education history and probes the concept of African Centered education, as well as explores the importance of including the family and community in the education of African American youth.

Mrs. Lillie Tyson Head responds to the presentation by Dr. Jacqueline Brooks’ keynote address on School as an Extension of Family with her presentation and article entitled The Necessary Roles of Family and the Purpose of Education.” Dr. Brooks is the Superintendent of the Macon County School System, located in Tuskegee, Alabama. She tells the story of the power and influence of a mother on the life of her child. The child was Booker T. Washington, the founding President of Tuskegee University. Mrs. Head, public school teacher herself, views words like family and education as essential in the context of ethical behavior. As the daughter of one of these men, Freddie Lee Tyson, she acknowledges that formal slavery no
Preface

longer exists but, the conditions that enslave intellectual growth and hinders achievement are ever-present. She recounts the many barriers that disrupt the teaching and learning process. In spite of the challenges in the schools, Mrs. Head calls for loving families and safe communities and nurturing family and welcoming communities where all can become their best selves. She reminds the reader that Booker T. Washington believed that freedom begins with education and education must occur on the university campus, but also in the community, at large.

Crystal James JD, MPH and Earl Robinson PhD contribute to this edition with their paper entitled, *Prelude to a Revolution: Expanding the Power of the Black Lives Matters Movement to Decrease Deaths Caused by Legal Intervention in the United States*. They use a mixed method approach to address legal intervention as a cause of death in the US and highlight the Black Lives Matter Movement to discuss the historical context, updating to current challenges related to intentional injuries of African Americans. The Black Lives Matter Movement (hereafter BLM) is crystallizing at a critical time in American history. Although its focus has been specifically on the treatment of African Americans by the repressive ideological and political structures of the United States, the group of young Black students, activists, and their allies has started a discussion that reverberates around the issues of race, ethnicity, and nationalism. By describing the national sources of intentional injuries by Law Enforcement in the US, their paper examines the genesis and possibilities of the BLM's Movement and the opportunity it has in crafting a more ethical description of the health disparities created by the state apparatus in its attempt to promote the general welfare of the people.

Reverend Julian Cook, M.Div., in his article "Religion, Ethnicity and Identity: Good Religion Must Rise Up," responds to Rev. Dr. Moni McIntyre's presentation entitled "Religion, Ethnicity and Identity." He references various disciplines and practices, including Black spirituals and other religious practices that protect all humanity, to discuss a good religion. Rev. Cook uses the scholarship of theologian, Paul Tillich, to explore how religion helps people to discern their “ultimate concern.” He cites Dr. Martin Luther King Jr., who argues that religion must address physical, as well as metaphysical concerns. Rev. Cook uses considerable space in his paper to highlight the pain and suffering experienced by African Americans. Yet, he reminds the reader of the immeasurable power of human potential. In spite the challenges of the human experience, Rev. Cook reminds the reader about the power of love.

The last article in this edition is written by Cesar Fermin PhD, Rafael Sanchez-Cardenas, MD and Caroline D. Fermin, BFA entitled, “Equitable Health Care to Minorities: An Ethical Dilemma Complicated by Corporate Profit and Misinformation.” The paper was presented during the Opening Session of a Public Health Ethics Forum, *Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection for Social Justice* held in April 2016 at the Centers for Disease Control and Prevention. The authors highlight, in their paper, the health literacy challenges posited by the popular press that misrepresents many of the salient issues related to health. They focus some of the article on Dominican Republic and the disparities in health expenditures targeted for medical care vs. public health, particularly for “minorities.” They highlight similar challenges in other developing countries like the Dominican Republic, and the U.S. While the U.S. and the Dominican Republic are different, in many ways, the public health challenges are similar. The paper provides scientific analyzes for contemporary health issues and practical approaches to address them. Without dismissing the gains in health and health care discovery and delivery, the authors point out that social justice violations challenge equitable benefit for all populations both in the U.S. and the Dominican Republic. They also challenge the ability of big business to serve in the best interest of patients, in the contexts of population health. The authors provide a list of conclusions about the health care which may apply to the U.S. and the Dominican Republic and other developing countries.

The articles in this edition posit a thought-provoking set of questions that need analysis, synthesis and action for the reader, the people they serve.
A Luminary Sheds Light on the ‘Legacy’ of the USPHS Syphilis Study at Tuskegee: Tracking Arthur Caplan’s Comments Over the Past Quarter-of-a-Century

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Author Note
The opinions expressed in this article are solely those of the author and do not necessarily reflect those of the institution where he is employed.

Abstract
This paper describes the views of Arthur L. Caplan, PhD, an internationally renown bioethicist, on the much discussed—and sought after—legacy of the infamous USPHS Syphilis Study at Tuskegee as expressed in his writings over the past quarter century. Over these 25 years Art Caplan has presented, in various meetings and written formats, a highly rational—and most consistent—point of view. Specifically, he holds that the legacy of the USPHS Syphilis Study at Tuskegee consists of the following individually identifiable elements: 1) caused America to rethink the ethics of human experimentation; 2) served to establish the field of bioethics and was a true catalyst for the rise of bioethics, and gave birth to modern bioethics; 3) was the major and immediate factor that led to the establishment IRBs in the U.S. and around the world to protect subjects; and, 4) served, as a case study, to identify racism and other forms of prejudice against vulnerables as the core issue of bioethics in U.S. and worldwide.

Keywords: Bioethicist, Bioethics, Clinical Ethics, Scientific Misconduct, History of Medicine

Introduction
“A luminary sheds light on the legacy of the U.S. Public Service Syphilis Study at Tuskegee.” We are all, in this room—myself most certainly included, and the families here even more certainly included—on a quest. What is the end result of that study? What did my relative—if you’re a family member—contribute to, other than being misled and being duped? What’s the goodness that came out of this infamous event?

And we’re all in search of that in different ways. I, from a research perspective, that’s my involvement. I had received a large NIH grant to run an oral health minority center, and there was a need to run studies on oral diseases that disproportionately affected African-Americans. In our case, we were focused in North New Jersey on oral cancer rates, 30% higher incidence in African-Americans than whites, a 50% higher mortality rate. At that time, in that community of Newark, NJ, we were also focused on pediatric AIDS, a newly emerging
Articles

I can give you an example of a controversy he’s not afraid to wade into. Having known Art for a couple of years now, I would say I don’t know that Art is absolutely always convinced that he’s always right. But do I think he’s convinced he has thought it through, come to a decision, and it’s time to act when he’s reflected long enough. “The obligation to act, as you’ll see in some of the quotes I’m going to give you, is core to his beliefs, and conversely, ‘if a bioethics conversation takes place between erudite university centers only, it’s a waste of everyone’s time, including those bioethicists.’”

Somebody’s got to speak to the public and make the dialogue involve the public so they’re informed of what are the issues, the controversies, the safeguards, as well as the limitations on those safeguards, and maybe then get even some ideas from the public on how to improve it.

And under that recent NY Times headline which read ‘Eager to Opine on the Toughest Calls in Medical Ethics’, the article went on to say: “he has made a successful career offering his opinions to physicians, institutions, and the news media”—and I’ll emphasize that last point, “the news media”—“about doctors, and how they should act.”

Here’s the telling details of ‘that call by Art’. So, we had a very recent controversy going on in the headlines of New York papers recently over Robert De Niro’s Tribeca Film Festival and his decision to air a controversial film on the issue of traditional childhood vaccines having caused autism as an adverse side-effect. And the fellow who created the ruckus—and I’ll use that word advisedly—out of England, was the same person who was the director of that film.

He was the very guy who did the ‘research’. The research, as it turns out, was done—literally—in a closet with a light bulb. He went into a closet with medical records and he changed all those project, in that NIH-funded Minority Oral Health Center, I led a research team into our Tuskegee Legacy Project, a study focused on trying to determine whether African-Americans were more reluctant to participate in biomedical research because of that infamous study in Tuskegee. So, this latter study was my personal quest on searching for the ‘legacy’.

So now let’s turn back to this ‘luminary sheds light’ theme. First, let’s just make sure we have common ground on this definition of ‘luminary’. We all have a notion of it. Number one, it’s a person of prominence or brilliant achievement. And then it is also a body that gives light, sheds some light on the subject matter. And Art Caplan has certainly contributed considerable light on this topic over the past quarter century.

Well, so we say: “Welcome to you, Art Caplan, welcome to the campus of Tuskegee University. And while I agree with the title of ‘luminary’ for you, I must confess that I borrowed it from another speaker, having heard the introduction to Art Caplan when he first came to NYU and gave his first public talk there in October of 2012. (Caplan, 2012) And when I heard that talk, that was the term used to describe Art Caplan by Dr. Allen Keller, the Director of the Masters Scholar Program in Humanistic Medicine at the NYU Center for Health and Human Rights. And, I thought he got the label exactly right.

First, just a quick review of what was told to you about Art Caplan in great detail by the person chairing this session today. Dr. Arthur Caplan, our Keynote Speaker at this opening session of this 2016 Public Health Ethics Initiative at the 19th Annual Commemorative Event for the Families and Survivors of the USPHS Syphilis Study at Tuskegee is currently the Director of the Division of Medical Ethics at the NYU Medical School, a division newly created to attract him to NYU. He has previously been the Director of the Center for Bioethics at the University of Pennsylvania, and before that, he was the founder of the Center for Bioethics at the University Minnesota. He was, before that, the Associate Director at the Hastings Center. And he is a frequent bioethics consultant to governments, U.S. and international, as well as to industry, as you heard through his talk on the topics he addressed today.

All that being true, I think his ‘luminary’ credentials arguably are as based upon his involvement with the popular press, as they are based on his considerable academic publications... and I’ll quote some things I found in looking that up. First, a New York Times article in 2015, just this past May, was headlined: ‘Eager to Opine on the Toughest Calls in Medical Ethics’. (NY Times, 2015) You know, I’ve heard the joke about a president of the U.S. asking desperately for one-handed economist as a consultant. And what he was referring to was his annoyance that anybody he got in as an economic consultant invariably wound up saying, “Well, on one hand, this will happen, and on the other hand, this will happen,” and the president is sitting there saying, “Well what do I do? You’re the expert.” Well, Art is no ‘two-handed bioethicist’ as he does make the toughest calls...clearly pointing the way with only one hand.

disease that had been vertically transmitted through IV drug users and to their children. And these youngsters were going to have a short life, and it was going to be even shorter due to oral manifestations of pediatric AIDS, and we had to find out what that was about and how we might control that. And we also did a baby-bottle caries study with welfare mothers, trying to give those mothers other means to achieve some quiet rather than a sweet bottle for the baby to put them to sleep, and ruin their teeth as sugar sat on their teeth when they slept, as salivary flow shuts down in sleep, and you get a very high risk dental caries situation. And, in addition to those project, in that NIH-funded Minority Oral Health Center, I led a research team into our Tuskegee Legacy Project, a study focused on trying to determine whether African-Americans were more reluctant to participate in biomedical research because of that infamous study in Tuskegee. So, this latter study was my personal quest on searching for the ‘legacy’.

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in medicinal treatments or surgical treatments, there’s malpractice in information dissemination as well, and they should lose their license if they commit informational malpractice. Now, that’s what they mean when they say Art Caplan makes tough calls out there.

He takes bioethics to a functional point. Not many bioethicists do that. Many seem to have two hands. They often appear to want to see a balance, and present a balanced opinion. Yet, Art Caplan clearly believes that you must get a point of making a call, in many issues, at some point when you have enough information and the public needs guidance.

“And at times, he has clashed with colleagues over medical questions.” How can you not, if you’re a bioethicist with only one hand? I’ll quote further from that New York Times article. “He has long been an advocate of disclosures to patients about risks and benefits of studies …and… has pushed doctors to disclose the financial benefits they received from drug and medical load-device companies.” Disclosure is necessary. It doesn’t mean you’ve been influenced by it. Let the people decide. But Art Caplan believes you should disclose it so people can consider that.

And finally, from that same article, “Art was quoted as having said in the 1991 medical ethics symposium,” (the one he referenced here this morning) that, “informed consent is a privileged man’s protection. It is not going to work as well for someone who is poor and uneducated and for whom the researcher may have prejudice and contempt. It works best for those are educated enough to demand it.”

That cautionary note about the protection of informed consent from Art Caplan is a boldly honest statement. And so, in Art Caplan, we have a bioethicist who hears, and sees, and thinks and reflects, and then speaks his mind publicly in the press, as well as in erudite scholarly journals. And that is one of Art Caplan’s unique skills. Clearly, he is fully capable of writing those erudite arguments with the polysyllabic words as well as anybody, arguments with fine distinctions drawn in meaning. But he also can boil it down to the essence and give a terse quote to a newspaper that gets right to the heart of it and makes it clear to everybody. In sum, we have a bioethicist who treats his own bad behavior with respect to the moral argument and the abuse of human subjects.

And obviously, he doesn’t like that idea. Art went on to say: “if we’re going to both move forward and do better now, we must understand why we are the way we are now,”

Then, I turn now to my question of what has this luminary said about the legacy of the USPHS Syphilis Study at Tuskegee? What’s his view on, what light has he shed upon the legacy? The method I used to gather the facts resorted to what I usually do as a researcher when I initiate a new project. I engaged a professional consultant called a biomedical librarian, who knows what they’re doing in the searching the literature, not me fumbling around to hope to find a few random apples. I wanted to shake the tree and get all apples to fall off. That biomedical librarian found over 600 published articles that Art Caplan had published. I then cross-referenced those 600 articles with the term “Tuskegee,” which resulted the identification of 11 published articles by Art Caplan in which he had addressed the USPHS Syphilis Study at Tuskegee. Five were original manuscripts on the topic (Caplan, 1992; Caplan, 1993; Caplan, 1994; Caplan, 1994; Caplan et al, 1994; Caplan, 2004) one a letter to the editor (Caplan, 1999), four were book reviews (Caplan, 2005; Caplan, 2007; Caplan, 2008; Caplan, 2014) and one was a commentary article in a newspaper (Caplan, 1997).

First, let me reference his inaugural 2012 talk at NYU that I spoke of earlier, which was entitled—and it’s why I that attended that lecture, because I knew Art would have something different to say on the topic— ‘German Medicine, Nazi Ethics and the Legacy of the Holocaust.’ (Caplan, 2012) So on October 12th, I heard Art say, ‘All of these [unethical] experiments in the [nineteen] fifties and sixties, including Tuskegee, used many of the same arguments the Nazis used in their own defense, but it was not until the Tuskegee study revelations in 1972 and the outrage about the racism and poor moral foundation for that experiment that bioethics really began.’ Start to hear what Art is saying here, as we look to discover what he sees as the legacy of the USPHS Syphilis Study at Tuskegee.

“People want to put,” he said, “the origins of bioethics in the Holocaust.” He went on, “I don’t think you can do so. It was marginalized, it was denied, it was seen as the actions of crazy people, the Nuremberg Code. But it’s a code for Nazis, and kooks, and nuts and that’s not us, and the Western world and Europe and America does not have to worry about that because we aren’t Nazis, we’re not Mengele…. We’re mainstream people, we know better, except that we continued to invoke the same moral rationales in the same nasty experiments for the next 30 years after the close of World War II, after the Holocaust. So, bioethics does not get its start there [with the Holocaust].”

Those are the words of Art in that talk. I know because I got a transcription service to transcribe his entire talk and I read it four times, so these are details that are taken directly—and accurately—from a written text, not from a screen rapidly flashing by while I’m trying to jot down notes.

“If we say,” he went on, “bioethics begins with the Holocaust, we write off 30 years of our own bad behavior with respect to the moral argument and the abuse of human subjects.” And obviously, he doesn’t like that idea. Art went on to say: “if we’re going to both move forward and do better now, we must understand why we are the way we are now,”

He goes and identifies one core cornerstone of today’s bioethics, “Why do we have informed consent [as an essential element]?” It’s in response to those Nazi arguments, the concept of informed consent.” He then moved from identifying the origin of that core essential element of informed consent to address how that core element was incorporated systematically and brought into action on behalf of the public as he asked: “Why do we now have those IRBs?” Why do we have all those IRBs and paperwork today as a guideline to proper behavior? Well, it’s because people bamboozled people in the Tuskegee study and got their consent under false pretense.

And where does he take that thought? “So, in sum, I don’t think things got good,” Art says, “at the end of the war. I think the Nuremberg Code is there, and I wish it were true that things got good as soon as the Nuremberg Code was put out, with respect to human subjects’ research. I don’t think they did for another 30 years,” Art states, “until after the Tuskegee Syphilis Study was made public, and I think that’s a part of the history that bioethics and people interested in the ethics of medicine have to face up to.” So, Art Caplan clearly states that the creation and existence of IRBs is, indeed, an identifiable legacy of the USPHS Syphilis Study at Tuskegee.

As an aside, I would note that the acronym ‘IRB’ stands for Institutional Review Board and lament that it is a term that ranks amongst the most meaningless terms I’ve ever heard. Why can’t it be some acronym that uses more descriptive, more meaningful words for ‘the use of human subjects in research,’ so all people can readily understand what it stands for? That lament said, that’s my aside.
So, let’s go back in time, then, from that first talk by Art Caplan in 2012 at NYU, and find out what Art said prior to that day, and take a chronological look at what our luminary has shed on the light of the Tuskegee study over the years prior to his NYU inaugural talk.

Twenty years prior, in 1992, in an article called, ‘When Evil Intrudes,’ in the Hastings Center Report, he said, “Americans found it hard to believe that the Public Health Service had intentionally and systematically duped men with a disease as serious as syphilis—contagious, disabling, and life-threatening—for more than forty years.” (Caplan, 1992) “The level of outrage,” he goes on to say, “about the Tuskegee study was enormous. As a result of public anger over the immorality of the study in 1972, Congress created an ad hoc blue ribbon panel to review both the Tuskegee study and the adequacy of existing protections for subjects in all federally sponsored research.” And he goes on to say, “Congress, two years later, in 1974, created the Human Commission for the Protection of Human Subjects for Biomedical and Behavioral Research, which laid the foundation for the ethical requirements that govern the conduct of research on human subjects in the United States to this day, i.e., the establishment of IRBs nationwide to ensure ethical practices in human research, which rapidly then became the worldwide standards.” In that 1992 ‘When Evil Intrudes,’ article, Art goes on to say, “The Tuskegee syphilis study played a crucial role in causing Americans to rethink the ethics of human experimentation.”

In a follow-up 1993 article (once again published in the Hastings Center Report) Art articulates his firm professional belief—and commitment to—speaking out in the lay press and other media on ‘hot issues’ in bioethics. (Caplan, 1993) In this 1993 ‘What Bioethics Brought to the Public’ article, he clearly stated his opinion that the practice of bioethics ultimately requires that some of the discussion on ‘hot topical bioethics issues’ take place in the public forum as he stated that “the road to taking place in public in this culture is through the media.”

He went on to say, “Stories in the Washington Post and the New York Times were the key to the beginning of the discussion about Tuskegee and later to the establishment of the National Commission and the regulations in the Belmont Report, which is what led to the IRB, led to the IRBs.” Specifically, he goes on to that 1993 article that, “[t]he early relationship between bioethics and the media was based upon scandal—Tuskegee—as well as other outrages.”

In 1994, in an article, ‘Are Existing Safeguards Adequate?’ he re-emphasizes his opinion that “[m]any people believe that it was the discovery of the cruel and barbarous experiments conducted by the German scientist and doctors in the concentration camps during World War II that led to the demand for the creation of ethical standards governing human research. But that is not so.” (Caplan, 1994) “Ultimately, the Nuremberg Code,” he said, “did not have much of an impact in the United States, as there was a great deal of research conducted in the 1940s, fifties, and sixties, which did not live up to the ideals and moral requirements expressed in the various codes of ethics issued post-World War II.” So, he is echoing himself in different settings, bringing this same message out. In that 1994 article, he said, “The recognition of the need for more oversight and regulation for those participating in biomedical research only arose in the mid-1970s.” Clearly, Art Caplan presents a consistent message over time on his views. He goes on, “The revelation in 1973 of the Tuskegee study led to a public outcry concerning the ethics of human experimentation.”

In 2005, in his review of a book by George Annas, Crossing Human Rights and Health Law Boundaries: American Bioethics, Art Caplan said, “It was the revelation of the maltreatment of subjects [in] experiments, such as the Tuskegee study, that produced new laws and regulations regarding the conduct of human research.” (Caplan, 2005) In a 2008 book review of a book edited by Bonnie Steinbock, The Oxford Handbook of Bioethics, as it appeared in the journal Lancet, he said, “A few of the founders of the field of bioethics have taken pen to hand and given their thoughts to the field’s origins.” And he goes on to specifics saying that “[s]ome date the discipline to 1969 and the founding of the first think tank devoted to the subject, the U.S. Hastings Center. Some lean towards 1971, citing the creation of the Joseph and Rose Kennedy Institute of Ethics at Georgetown University. Some go back to the Nuremberg trial of Nazi doctors. Others see bioethics as having its birth in the ‘Tuskegee scandal in 1972.’ And he concluded in that same 2008 book review that ‘Bioethics began, in my view’—that is in Art Caplan’s view—“in response to scandal and uncertainty about the abuse in the Tuskegee experiment.”

His 2007 book review of James Jones’s book, Bad Blood, considered to be the definitive history of the U. Public Health Service Syphilis Study at Tuskegee, opens with this bold and startling line: “Bad Blood: The Tuskegee syphilis experiment is the single most important book ever written in bioethics.” (Caplan, 2007) And even he is evidently a bit perplexed himself for having made that statement, for he follows with: “Some may find this an odd choice since Bad Blood is not written by a bioethicist, theologian, philosopher, or physician.” And he goes on to say, “The book is not an essay on the theoretical or even applied ethics. I don’t think the term bioethics appears anywhere in the book.” Finally, in his book review of ‘Bad Blood,’ Art goes on then to say, “Bioethics did not flourish in the United States or anywhere else in the 1950s and sixties.” Adding that “The revelation of the Tuskegee syphilis experiment in 1972 broke decades of relative silence about the dubious practices [in] human experimentation in the U.S. and Europe and fueled the explosions of interest in bioethics in the U.S., which subsequently split over to the world.” And as he comes close to the end of his review, he adds: “What Jones’s book also did was to go to the root cause of the Tuskegee study—racism.” So, you can build a highway and you can have signs on it, but you better have some cautionary controls along the way for what humans will do with information, even within guidelines. And he goes on to say this: “Tuskegee and Jones’s book were the true catalysts behind the rise of bioethics.”

And then he comes out with one of these lines that is one of those memorable well-crafted lines that you can quote forever: “Tuskegee gave birth to modern bioethics and James H. Jones was the midwife.” Certainly, it’s a beautifully summative, and very clear, vision of his viewpoint.

In 2014, Art Caplan concluded his to date published views on the ‘legacy’ of the infamous Tuskegee Syphilis study in another book review that he did of a book that I had the privilege of co-editing with Dr. Reuben Warren, the Director of the National Center for Bioethics in Research and Health Care entitled The Search for the Legacy of the USPHS Syphilis Study at Tuskegee. (Caplan, 2014) He opened his review with this statement: “This is an important book. Not because it sheds new factual light upon the notorious 40-year study. The importance lies elsewhere. This is a book about a relatively unexamined aspect of this
incorporate Art Caplan's considered views in with our own. Our quest for 'the legacy' will perspectives—each of us having been on our own quest for 'the legacy', can now consider and societal level-impact. So, we all in this audience—for our own reasons, from our individual constitutions 'the legacy' …it's a given that his views are serious, thoughtful and views with empirical studies summarized in the book." “What seems evident,” he concludes, “as one reads the various essays in this volume, is that the protections that were built did not attend directly and openly to the major factor that permitted the U.S. Public Health Service Syphilis Study at Tuskegee to be undertaken—racism.”

So even with all that came out of the USPHS Syphilis Study at Tuskegee, with its impact on the field of bioethics, and with its legacy as defined by Art Caplan in his writings over the past quarter century, we still must watch over the system, ever prone to vulnerable persons being taken advantage of by others who see a moment of profit. And that’s basically it. “Still,” he says, “the real legacy of the U.S. Public Health Service Syphilis Study at Tuskegee is how hard it remains to admit to and respond to racism both in biomedical research and American society in general.”

“"The legacy of the U.S. Public Health Service Syphilis Study at Tuskegee," he says, "is that racism fueled the study, shaped the response that evolved, and continues to frame how we think about research ethics in the U.S. and increasingly in other parts of the world as more and more clinical research is outsourced to the poor and developing nations.”

Table 1 provides examples of what has our luminary said, a tracking of many of his quotes over this past quarter century. So, in summary, what’s his view on, and what light has he shed upon the legacy? In his writings over the past quarter century, Art Caplan has stated that the legacy of the USPHS Syphilis Study at Tuskegee consists of the following individually identifiable elements:

1) caused America to rethink the ethics of human experimentation—America, the whole society.
2) established the field of bioethics and was a true catalyst for the rise of bioethics, and gave birth to modern bioethics.
3) was the major and immediate factor that led to the establishment IRBs in the U.S. and around the world to protect subjects which is our current best level of safeguard developed, ...not perfect, but a big improvement over what wasn’t there before.
4) and then finally—and this still remains a concern to deal with everywhere in the world—identified racism and other forms of prejudice against vulnerables as the core issue of bioethics in U.S. and worldwide.

And given that the man, Art Caplan, has made those statements over time on what constitutes 'the legacy' ...it’s a given that his views are serious, thoughtful and views with societal level-impact. So, we all in this audience—for our own reasons, from our individual perspectives—each of us having been on our own quest for ‘the legacy’, can now consider and incorporate Art Caplan’s considered views in with our own. Our quest for ‘the legacy’ will continue as we know that we haven’t got the final answer yet. Nevertheless, as we note Art Caplan's four benchmarks of the tangible benefits, I think everyone who's been associated with or effected by this event, especially family members, can take home as reassuring knowledge that there was, beyond any doubt, some good that came out of this biomedical horror.

So, Art Caplan, for the good—and good-thinking—that is articulated in the reflection and writings that you’ve done over the past quarter century on ‘the legacy’ of the USPHS Syphilis Study at Tuskegee, we thank you. Thank you for shedding light on the ‘legacy’ that has emerged from this painful event in our history.

**Table 1.** Historical summary of bioethicist Art Caplan’s statements on the impact and importance of the USPHS Syphilis Study at Tuskegee: the quarter century from 1992-2016.

**1992**
- “Why do we have informed consent as central.... Well it's because people bamboozled people in the Tuskegee study...got their consent under false pretense.”
- “If we say bioethics begins with the Holocaust, we write off 30 years of our own bad behavior with respect to moral argument and the abuse of human subjects.”
- “...I wish it were true that things got good as soon as the Nuremberg Code was put out...I don’t think they did for another 30 years” ...until after the Tuskegee study is made public] ...as the level of outrage about the Tuskegee study was enormous.”

*in ‘When Evil Intrudes’, Hastings Center Report*

**1994**
- “Unfortunately, the Nuremberg Code...did not have much of an impact in the United States ...[through]...” the late 1940s, 1950s and 1960s...”
- “The recognition of the need for more oversight and regulation for those participating in biomedical research only arose in the mid-1970’s”
- “The revelation...of the Tuskegee study led to a public outcry concerning the ethics of human experimentation.”

*in ‘Are Existing Safeguards Adequate’, Calif Alliance Mental Illness*

**2005**
- “[It was] ...the revelation of maltreatment of subjects in experiments such as the Tuskegee study [that] produce new laws and regulations regarding the conduct of human experimentation.”

2007:
- "Bad Blood: The Tuskegee Syphilis Experiment [by James Jones] is the single most important book ever written in bioethics."
- "Bioethics did not flourish in the United States or anywhere else in the 1950s and 1960s."
- "The revelation of the Tuskegee syphilis experiment in 1972...fueled the explosions of interest in bioethics in the U.S., which subsequently spilled over into Europe and the rest of the world."
- "Tuskegee gave birth to modern bioethics and James H. Jones was the midwife."
- "What Jones' book also did was to go to the root cause of the Tuskegee study—racism."
- "Tuskegee and Jones' book was the true catalyst behind the rise of bioethics."


2014:
- "This is an important book...about a relatively unexamined aspect of this most famous violation of research subjects in American history—what is the legacy of the Tuskegee Study?"
- "It is also an article of faith that the field of bioethics arose as reaction to the Tuskegee Study...although it must be noted that the field really emerged in the early 1980s fueled...by attention to the USPHS Syphilis Study at Tuskegee."
- "What seems evident, however, as one reads the various essays in this volume, is that the protections that were built did not attend directly and openly to the major factor that permitted the USPHS Syphilis Study at Tuskegee to be undertaken—racism."
- "The legacy of the USPHS Syphilis Study at Tuskegee is that racism fueled the study, shaped the response that evolved and continues to frame how we think about research ethics in the USA and increasingly in other parts of the world as more and more clinical research is outsourced to the poor in developing nations."


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Health Literacy and Ethical Considerations for Health Equity in the New Public Health Era

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Abstract
This commentary is in response to some of the points raised in the keynote speech, “Public Health Policy Impacting Families and Community,” delivered by Bailus Walker, Jr., Ph.D., M.P.H. at the 2016 Public Health Ethics Intensive Course (PHEIC) at the Tuskegee University, regarding the role/importance of health education and the challenges faced by health education in helping address the inequities in the uptake of potentially beneficial interventions for lifestyle changes among various U.S. population groups. In his keynote address, Dr. Walker stated that: “despite advances in literacy and education as well as major improvements in communication...in this period of unprecedented acceleration in the pace of scientific and technological advances, and the educational focus on Science, Technology, Engineering and Mathematics (STEM)...there will still be a great gap between medical (protective) knowledge and the public acceptance of it.” He illustrated this assertion with a couple of examples: the lack of detectable decline in obesity rates despite clinical and public health efforts aimed at obesity reduction; and, despite wide spread smoking cessation programs including legislative interventions, tobacco use is still the underlying leading cause of death in the U.S.” He concluded that, “the endpoint of health education is not just awareness of facts but an emotional conviction toward both attitudinal and behavioral changes. Providing concrete knowledge of health and health-related issues is less important than insight, renewing interest, and nurturing values that can achieve a healthful lifestyle.”

Keywords: health literacy, health education, health promotion, health disparities

Introduction
This author agrees with Dr. Walker’s conclusion that the end product of health education efforts should not be merely the raising of awareness of facts about health and/or health related issues. However, this author submits that “the missing link” between health education (action/intervention) and desired behavior change (goal) is the inability of the target audience to fully understand and personalize health information due to limited or lack of “health literacy”? The following essay is the rationale for this assertion.

Concurrently with the unprecedented acceleration in the pace of scientific and technological advances mentioned by Dr. Walker, the United States of America, and indeed the whole world, is entering a “new public health” era in which there is increasing appreciation of the role of socio-political factors as determinants of the health status of various population groups. The differential effects of socio-political factors among the population groups create differential distribution of assets and resources necessary for health maintenance, thus creating health inequities and resultant differential in indices of health outcomes among population groups (i.e., health disparities). Concurrently with the need to better understand the pathways by which socio-political factors determine population health, there is the emerging explosion of advancements in genomics and information technology. These tools are increasingly being employed in efforts to address the inequities in health and health disparities. However, technological and genomic interventions, while immensely important, will not deliver on their lofty promises without concerted political and societal will to resolve the social determinants of health.

Health equity and health disparities are intertwined; therefore, it is important to provide some operational definitions of these terms. Margaret Whitehead (1992) defined Health Inequity as health differences that are avoidable, unnecessary, and unjust. Health equity, therefore, means social justice in health (i.e., no one is denied the possibility to be healthy for belonging to a group that has historically been economically/socially disadvantaged). Health disparities are the metric we use to measure progress toward achieving health equity. A reduction in health disparities (in absolute and relative terms) is evidence that we are moving toward greater health equity. Moving toward greater equity is achieved by selectively improving the health of those who are economically/socially disadvantaged, not by a worsening of the health of those in advantaged groups. (Whitehead and Dahlgren, 2006).

Equity is not the same as equality (Braveman and Gruskin, 2003). Health equity is achieved when every person can “attain his or her full health potential” and no one is “disadvantaged from achieving this potential because of social position or other socially determined circumstances.” Health disparities or inequities are types of unfair health differences closely linked with social, economic or environmental disadvantages that adversely affect groups of people. The sentinel IOM report titled “Unequal Treatment” highlighted the differential treatment (disparities in treatment) that segments of the population receive even when they get access to health care. Achieving health equity, eliminating disparities, and improving the health of all groups is an overarching goal for Healthy People 2020 and a top priority for the U.S. Department of Health and Human Services (DHHS). To improve health on the local, state, and national level, communities are encouraged to identify and address social determinants of health and improve these conditions through environmental changes. [Brennan Ramirez LK, Baker EA, Metzler M., Promoting Health Equity: A Resource to Help Communities Address Social
Determinants of Health, Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC); 2008.]

Applications of genomic and information technology will guide health related interventions and decision-making for personalized health care. Both health care providers and the populations they serve will increasingly rely on information technology for accessing, retrieving and using available health information in making decisions about disease prevention, health maintenance, and medical treatment options. This scenario assumes (albeit wrongly) that everyone has equal access to health information because of the pervasive availability of the internet and mobile phones, and that everyone can use the information. However, as pointed out in Dr. Walker’s thought-provoking speech, “...despite advances in literacy and education as well as notable improvements in methods of communication there still exists a significant gap between existing medical and health protective knowledge and the public’s acceptance and use of it.” The failure so far to effect tangible decline in the evolving obesity epidemic in the United States was cited as an example of the public’s limited acceptance and use of widely disseminated health protective information on diet and exercise. This is a clear illustration of the inherent limitations of health education as a health promotion tool – delivery of information to hopefully improve knowledge in the absence of self-efficacy is not sufficient to guarantee the desired behavior change. Getting a horse to the river is not sufficient, if the horse refuses to drink available water!

This new public health era poses both technological and moral challenges to health professionals, policy makers, and the society in general. As Dr. Walker said, “…all citizens will need to be better informed, whether in the doctor’s office or at the polling place.” Don Nutbeam (2000) enumerated three categories of “health promotion outcomes” as “the bridge” between what we do and what we are trying to achieve in health promotion interventions – the bridge between an intervention (or health promotion actions) and the goal of the intervention (modification of the determinants of health). Health promotion outcomes necessary to be achieved between an intervention (i.e., intervention impact) and desired goal are: improvements in health literacy, social action and influence, and healthy public and organizational practices. Arguably, the first necessary health promotion outcome is health literacy which can instill the self-efficacy needed for social action and influence to produce healthy public policy and organizational practice. Unfortunately, half of all American adults (including many White native-born Americans) have marginal or inadequate (low) health literacy (Eichler, 2009). According to the 2003 National Assessment of Adult Literacy (NAAL) by the U.S. Department of Education, only 12 percent of English-speaking adults in the United States have proficient health literacy skills (DHHS ODPHP, 2010; #2). The changing demographics in the United States compounds this situation, especially the increase in immigration of many diverse non-English-speaking racial and ethnic population groups with different languages and cultures, low-income populations, and those older than 65 years with limited schooling (Center for Health Care Strategies, 2009). Health insurance literacy is also low, particularly among those with low income (Barcellos, 2014; Urban-Long, 2014), the uninsured, and racial and ethnic minorities (Urban-Long, 2014).

What is Health Literacy?

The term health literacy has been used in the health literature for at least 30 years (Ad Hoc Committee on Health Literacy, 1999). In the United States, in particular the term is used to describe and explain the relationship between patient literacy levels and their ability to comply with prescribed therapeutic regimens (Ad Hoc Committee on Health Literacy, 1999). This approach infers that ‘adequate functional health literacy means being able to apply literacy skills to health-related materials such as prescriptions, appointment cards, medicine labels, and directions for home health care’ (Parker et al., 1995). Research based on this definition has shown, e.g. that poor functional health literacy poses a major barrier to educating patients with chronic diseases (Williams et al., 1998), and may represent a major cost to the health care industry through inadequate or inappropriate use of medicines (National Academy on an Aging Society/Center for HealthCare Strategies, 1998). However, this fundamental but somewhat narrow definition of health literacy misses much of the deeper meaning and purpose of literacy for people.

The field of literacy studies is alive with debate about different ‘types’ of literacy and their practical application in everyday life (Nutbeam, 2000). One approach to classification simply identifies three types of literacy not as measures of achievement in reading and writing, but more in terms of what it is that literacy enables us to do (Freebody and Luke, 1990):

1. Basic/functional literacy—sufficient basic skills in reading and writing to be able to function effectively in everyday situations, broadly compatible with the narrow definition of ‘health literacy’ referred to above.

2. Communicative/interactive literacy—more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.

3. Critical literacy—more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations.

Such a classification indicates that the different levels of literacy progressively allow for greater autonomy and personal empowerment. Progression between levels is not only dependent upon cognitive development, but also exposure to different information/messages (communication content and method). This, in turn, is influenced by variable personal responses to such communication—which is mediated by personal and social skills, and self-efficacy in relation to defined issues. By contrast to the definition of functional health literacy above, World Health Organization (WHO) defines health literacy more broadly, as follows (Nutbeam, 1998): Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people’s access to health information and their capacity to use it effectively, health literacy is critical to empowerment. This definition reflects elements of the two other types of literacy described above — interactive and critical literacy. It also significantly broadens the scope of the content of health education and communication, indicates that health literacy may have both personal and social benefits, and has profound implications for education and communication methods.

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Health literacy is clearly dependent upon levels of fundamental literacy and associated cognitive development. This author submits that “the missing link” between health education (action/intervention) and desired behavior change (goal), the inability to fully understand and personalize health information, is low/limited or lack of “health literacy”? Individuals with undeveloped skills in reading and writing will not only have less exposure to traditional health education, but also less developed skills to act upon the information received. For these reasons, strategies to promote health literacy will remain intrinsically tied to more general strategies to promote literacy. But beyond this fundamental link between literacy and health literacy, much of the richness of health literacy implied by the WHO in definition is missed in approaches to the promotion of functional health literacy as described above. Having emphasized this fundamental relationship, however, it is important to recognize that high literacy levels (assessed in terms of ability to read and write) are no guarantee that a person will respond in a desired way to health education and communication activities. By contrast, Freire, and those that have modelled their education programs on his methods (Wallerstein and Bernstein, 1988), have shown that working to raise the ‘critical consciousness’ of those with little or no skills in reading and writing can undertake activities and achieve outcomes which are closely aligned to the definition of critical literacy described above. The Institute of Medicine (IOM) defines health literacy as the degree to which people obtain, process, and understand basic health information and services to make appropriate health decisions (IOM, Nielsen, Bohman, 2004). Health literacy requires knowledge from many topical areas, including the body, healthy behaviors, and the workings of the health system (DHHS ODPHP 2010).

Impact of Low Health Literacy

In 2000, Healthy People 2010 identified limited health literacy as a public health problem based on several scientific evidence and systematic reviews of the literature on the effects of limited literacy on health outcomes and set national objectives for its improvement (DHHS ODPHP 2010, sect. 4 and 5). Inadequate or low health literacy significantly compromises an individual’s participation in health education process, information-seeking practices, and navigation and accessing health care systems (Wilson, 2003). People with poor health literacy may have problems communicating with their physician, reading instructions and labels on medicines, completing medical and insurance forms and understanding many other health literacy as the degree to which people obtain, process, and understand basic health information and services to make appropriate health decisions (IOM, Nielsen, Bohman, 2004). Health literacy requires knowledge from many topical areas, including the body, healthy behaviors, and the workings of the health system (DHHS ODPHP 2010).

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Approaches to Improve Health Literacy

Health education by its practice is directed towards improving health literacy, which in turn is linked to many other psychosocial issues mentioned previously (Nutbeam, 2000). But, improvement in health literacy should be a clearly defined outcome of health education and health promotion efforts, not an after-thought or left to chance. Evidence-based strategies demonstrating that limited health literacy can be successfully addressed are emerging from the fields of communication, health care, public health, and adult education. Approaches to improve health literacy include simplifying targeted health education materials (written, video, audio, and computer formats), improving patient-provider communication, plain language and pictogram medication sheets, and improving overall literacy (DHHS ODPHP, 2010, pp. 47-50). However, with increases in number of successful evidence-based interventions, important questions remain: What are the most effective strategies for improving health literacy skills? How can the health care system change to better meet the information and communication needs of all people? (DHHS ODPHP).

Improving health literacy is critical to achieving the objectives set forth in Healthy People 2020 and, more broadly, key to the success of current national health agenda. In addition to the Healthy People 2020 initiative, there are many of initiatives by Federal agencies and national non-government organizations (NGOs) to address the problem of low health literacy at national, state and local levels. Following are some select few examples:

The National Action Plan to Improve Health Literacy

The Action Plan envisions a restructuring of the ways we create and disseminate all types of health information in this country. The plan also calls on us to ensure that all children graduate high school with health literacy skills that will help them live healthier throughout their lifespan (DHHS ODPHP, 2010, pg. iii). The plan sets forth achievable objectives and describes what is required to create and sustain a health literate Nation – while recognizing that actions are required to simultaneously address the multiple socio-political determinants of health. Some health professional organizations have rallied to answer the national call to action. For example, the oral health field produced agenda for health literacy in A National Call to Action to Promote Oral Health and research dentistry.

The development of health policy, programs, and financing must address the need for increased usability of health information and services. The National Action Plan to Improve Health Literacy seeks to engage organizations, professionals, policymakers, communities, individuals, and families in a linked, multi-sector effort to improve health literacy. The Action Plan is based on 2 core principles:

- All people have the right to health information that helps them make informed decisions
- Health services should be delivered in ways that are easy to understand and that improve health, longevity, and quality of life

The vision informing the plan is of a society that: Provides everyone with access to accurate and actionable health information; delivers person-centered health information and services; and, supports lifelong learning and skills to promote good (optimal) health.
The Action Plan contains 7 goals that, when achieved, will improve health literacy and strategies for achieving them:

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable
2. Promote changes in the health care system that improve health information, communication, informed decision-making, and access to health services
3. Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in child care and education through the university level
4. Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community
5. Build partnerships, develop guidance, and change policies
6. Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy
7. Increase the dissemination and use of evidence-based health literacy practices and interventions

Many of the strategies highlight actions that particular organizations or professions can take to further these goals. It will take everyone working together in a linked and coordinated manner to improve access to accurate and actionable health information and usable health services. By focusing on health literacy issues and working together, we can improve the accessibility, quality, and safety of health care; reduce costs; and improve the health and quality of life of millions of people in the United States. (http://health.gov/communication/initiatives/health-literacy-action-plan.asp)

The Patient Protection and Affordable Care Act of 2010 (Title V)

While the Affordable Care Act of 2010 (ACA), with universal coverage, assures access to care for all Americans and protects against refusal of coverage based on pre-existing health conditions, studies of health literacy found that health insurance literacy is also low, particularly among those with low income (Barcellos, 2014; Long, 2014), the uninsured, and racial and ethnic minorities (Urban-Long, 2014) – precisely those the Act was designed to help most. Sections 3501 (Health Care Delivery System Research, Quality Improvement Technical Assistance), 3506 (Program to facilitate Shared Decision-making), 3507 (Presentation of Prescription Drug Benefit and Risk Information), and 3501 (Training in Family Medicine, General Internal Medicine, General Pediatrics, and Physician Assistantship) in the Act have direct references to “health disparities” (National Academy of Sciences, 2011). A survey by the Texas Department of Health found that many potential applicants for insurance coverage under the Act are unfamiliar with basic health insurance lingo such as “premiums” and “copayment” (HealthDay online). In Washington, DC, the problem with the newly established DC Health Benefit Exchange is ensuring access by opening 21 more clinics in underserved areas of the city for newly insured; the DC experience has been that “...there is no provider in the (underserved) community who will take their insurance card” (Mohammed Akhter, APHA Public Health Newswire, 2013).

The National CLAS Standards

In 2000, the U.S. DHHS Office of Minority Health (OMH) developed the National Standards on Culturally and Linguistically Appropriate Services (CLAS) to provide a common understanding and consistent definitions of culturally and linguistically appropriate services in health care. Culturally and linguistically appropriate services consistent with the 15 National CLAS Standards help individuals and organizations respond to the demographic changes in the United States; reduce health disparities; improve the quality of services; meet legislative, regulatory and accreditation mandates; gain a competitive edge in the market place; and decrease the likelihood of liability. Essentially, the National CLAS Standards pride a blueprint for individuals and health care organizations to best serve the Nation’s increasing diverse communities through culturally and linguistically appropriate services (OMH 2000). These standards were intended to be practical framework for providers, payers, accreditation organizations, policymakers, health administrators, and educators. Post-reform efforts to address health literacy should make use of the resources available through the OMH to ensure implementation of the CLAS standards. The newly created Patient Centered Outcomes Research Institute (PCORI) is tasked under the ACA with conducting evaluative comparative effectiveness research and ensuring that subpopulations, particularly communities of color, are represented in research designs (National Academy of Sciences, 2011). These provisions could help to answer the questions of: What are the most effective strategies for improving health literacy skills? How can the health care system change to better meet the information and communication needs of all people?

The Surgeon General’s National Prevention Strategy

The National Prevention Strategy, released in June 2011, aims to guide the nation in the most effective and achievable means for improving health and well-being. The Strategy prioritizes prevention by integrating recommendations and actions across multiple settings to improve health and save lives. The Strategy envisions a prevention-oriented society where all sectors recognize the value of health for individuals, families, and society and work together to achieve better health for Americans. (DHHS Office of the Surgeon General, 2011). The vision is that, working together to improve health and quality of life for individuals, families, and communities by moving the nation from a focus on sickness and disease to one based on prevention and wellness. The goal is to increase the number of Americans who are healthy at every stage of life. The Strategic Directions provide a strong foundation for all of America’s prevention efforts and include core recommendations necessary to build a prevention-based strategy. The four Strategic Directions are: Healthy and Safe Community Environment; Clinical and Community Preventive Services; Empowered People; and, Elimination of Health Disparities. Together, the Strategic Directions create the web needed to fully support Americans in leading longer and healthier lives.
Within the Strategy, the Priorities provide evidence-based recommendations that are most likely to reduce the burden of the leading causes of preventable death and major illness. The Priorities are designed to improve health and wellness for entire U.S. population, including those groups disproportionately affected by disease and injury. The seven Priorities are: Tobacco-Free Living; Preventing Drug Abuse and Excessive Alcohol use; Healthy Eating; Active Living; Injury and Violence Free Living; Reproductive and Sexual Health; Mental and Emotional Well-being.

As posited by Nutbeam (2000), outcomes of health education and health promotion can empower individuals and communities for social action and influence toward healthy public policy and organizational practice. A Strategic Direction necessary for achieving the goal is “Empowered People”: people are empowered when they have the knowledge, ability, resources, and motivation to identify and make healthy choices. Empowered people are able to take an active role in improving their health, support their families and friends in making healthy choices, and lead community change.

Cooperative Extension’s National Framework for Health and Wellness (Role for Land-Grant Universities)

The Surgeon General’s National Prevention Strategy recommends that we (i.e., Land-Grant Universities); provide people with tools and information to make healthy choices; promote positive social interactions and support healthy decision making; engage and empower people and communities to plan and implement prevention policies and programs; and improve education and employment opportunities. These recommendations can help address the socio-political issues affecting the health and quality of life of individuals and communities. The Strategy also prescribes specific actions for Early Learning Centers, Schools, Colleges and Universities: Provide input, guidance, and technical assistance to State, tribal, local, and Territorial health departments in assessing health impacts and conducting comprehensive health improvement planning; and, incorporate health education into coursework (e.g., by embedding health related tasks, skills, and examples into lesson plans).

In 2012, America’s land-grant universities that are members of the Nation’s Cooperative Extension System established the Extension Committee on Organization and Policy (ECOP) Health Task Force (ECOP Health Task Force) to identify priorities for the Cooperative Extension’s health programs for the next 3-5 years and appropriate outcome indicators as well as potential partners that could be engaged in resource development, program implementation and outcomes reporting. The ECOP Health Task Force decided it was essential to align the Extension’s national framework for health and wellness with the U.S. Department of Health and Human Services’ National Prevention Strategy: Strategic Directions. In doing so, the Task Force developed a national strategic direction that can both increase awareness of the value of prevention across multiple sectors and further support a comprehensive approach to preventing illness and disease by promoting health and wellness. Hence, in direct alignment with the National Prevention Strategy model, the overall goal of the Cooperative Extension health and wellness framework is to “Increase the number of Americans who are healthy at every stage of life.” The Cooperative Extension’s framework utilizes the Social-Ecological model as its theoretical base – a model which is applicable for studying the pathways by which social factors interact to influence individual and community health outcome. The model considers the complex interplay between individual, community, and social factors, including an individual’s attitudes, beliefs, behaviors and choices. The social-ecological aspects are identified in the model as “healthy and safe choices” and “healthy and safe environments”, and the interplay between these factors (ECOP, 2014).

America’s land-grant universities (such as Tuskegee University) have the knowledge and expertise needed to help address the health and socio-political issues of concern to the nation and the Surgeon General/ the U.S. Department of Health and Human Services (DHHS). Through county Extension offices, the universities have the community presence and local credibility needed to influence the social, economic and environmental determinants of health. The universities have the capacity to meet the Actions identified for colleges and universities in the National Prevention Strategy by providing technical assistance in helping deploy evidence-based interventions in ways that are respectful of community, individual and family norms, beliefs, and current practices in a way to help keep people healthy, and delay or prevent the need for medical care.

Based on an assessment of the Cooperative Extension’s assets and limitations relative to health programming, the ECOP Task Force established the following six Strategic Program Priorities: Integrated Nutrition, Health, Environment, and Agricultural Systems; Health Literacy; Health Insurance Literacy; Chronic Disease Prevention and Management; Positive Youth Development for Health; and, Health Policy Issues Education. The Task Force has also developed a logic model based on the framework to guide the development of indicators for evaluation of the implementation and outcomes/ impact of each priority.

Collaborations across Sectors: In addressing social determinants of health beyond the scope of the U.S. Department of Health and Human Services (DHHS’) Mission

Addressing many of the socio-political and economic issues are beyond the scope of the mission of the U.S. Department of Health and Human Services (DHHS). To accelerate health equity and address concerns regarding social determinants of health in this era of health care and public health, collaborations are required across sectors such as education, justice, housing, and labor and confront the structural forces and social, economic, and political influences on the health of our communities.
Conclusion

Health education and health promotion are necessary for addressing modifiable determinants of health and in empowering individuals and communities to make health choices and live in healthy safe environments. As Dr. Walker pointed out in his keynote speech, "...the endpoint of health education is not just awareness of facts but an emotional conviction toward both attitudinal and behavioral changes." This author believes that the goals of health education and health promotion cannot be achieved without improving the level of health literacy in American society. Improving health literacy will require innovative strategies at local, State, and national levels by educators and health professionals as well as health professional organizations. Addressing the socio-political and economic circumstances that result in less than optimal health outcomes, however, will require collaborations across sectors beyond the Department of Health and Human Services. We all have a role to play if the various national and local goals are to be achieved. Processes, infrastructure and resources for evaluating various interventions/actions are critical for identifying successful evidence-based interventions that should be supported and scaled-up, as well as identifying those interventions that are not working and need to be redesigned or discontinued.

References


The Evolution of Family: 
From Trauma Narrative to Healing Narrative

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Author Note
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Abstract
Using cultural trauma theory, personal and public narrative, this article examines the concept of family evolution in the context of African American identity formation and its relationship to a social history of racial hierarchy in America. Embracing an expanded notion of family that includes ancestral lineage, communal association, and future generations, emphasis is placed on narrative change in service to racial truth, healing, and transformation.

Keywords: cultural trauma, narrative change, racial healing, post-traumatic slave syndrome

Introduction
It is against the historical backdrop and social context of the U.S. Public Health Service Syphilis Study at Tuskegee conducted between 1932-1972, without informed consent, that I examine the topic, “The Evolution of Family: From Trauma Narrative to Healing Narrative.” Utilizing trauma theory as a framework for this discussion, I turn to the work of sociologist Ron Eyerman, who directs attention to slavery, an undeniably traumatic experience, as a marker in the formation of an African American identity. However, it is not the direct experience of slavery that Eyerman would have us focus on, but the collective memory of it and how that memory played a significant role in the making of an African American identity (Eyerman, 2004). This collective memory, as Eyerman argues, provided a mobile narrative that could transcend time and space and could be spoken, painted, sung, danced, written in poetry or prose and serve as a means of building social cohesion and ultimately an African American identity, an identity rooted in an historical, cultural trauma. He refers to memory as a “signifying practice,” one that represents something of significance (Eyerman, 2004).

Likewise, a group of surviving family descendants of the 623 African American men who participated in the Syphilis Study gathered in conference with scholars, medical doctors, health care providers, social workers, community leaders, educators, and ministers, as well as graduate and undergraduate college students to participate in a ritual of remembrance, a “signifying practice.” They gathered to commemorate the 19th Anniversary of the Presidential Apology for an act of social injustice and inhumane treatment experienced by the participants of the study. However, it was not just the presidential pardoning that was being remembered, it was the story of exploitation and disregard for the subjects, their families and descendants. It was the stories of shame and horror, mistrust and caution that this study precipitated among black people in the country. It was another instance of an African American experience of trauma, but it was also an instance of movement from a trauma narrative to a healing narrative.

Narrative Change
The healing narrative emerged through the work of several descendants who came together under the leadership of Lillian Tyson Head to form “The Voices for Our Fathers Legacy Foundation” in 2014, “To uplift the legacy of the USPHS Study in Macon County by honoring the men in the study and convening their families to preserve history and enrich education in clinical and public health research (Head, 2014).” Agreeing to work together to transform the legacy of their fathers, the members also established a memorial garden, a sacred space at Tuskegee University, for “healing, inspiration and reflection,” a reminder of the ethical and moral guidelines that must be followed in the conduct of human subject research. The establishment of the Legacy Foundation provides a clear example of narrative movement from the trauma of learning about the study in 1973 to the decision to re-author the narrative and establish a foundation and memorial garden in 2014, some 40 years later.

Narrative coaching theory provides a helpful framework for analyzing the narrative movement and subsequent action. The four stages of narrative change underlying individual or collective change, as defined by David B. Drake, include 1) situate, 2) search, 3) shift, and 4) sustain (Drake, 2015). Each stage is an aspect of narrative awareness and processing. In the case of the USPHS Syphilis Study, the first stage, situate, begins when the descendants of the participants first heard the story. They were forced to come to terms with the emotional responses to this trauma narrative. The shock, disbelief, and anger most likely led to a search for answers. How could this happen? Why? What did it all mean? Who were the surviving descendants? How could they be contacted? Would they be too embarrassed to step forward? The Tuskegee University National Center for Bioethics in Health Care and Research was established in 1999 with the mission of transforming the negative legacy of clinical research among African Americans, through a regular series of events, lectures, workshops, and conferences. The center has provided a base of support from which the syphilis study descendants could ritualize the memory of their fathers and transform the narrative. Through its programs of education and awareness, the Bioethics Center moved the narrative to the stage three, shift, and stage four, sustain.

The movement from trauma narrative to healing narrative can be found in a variety of case studies documenting the social history of African America people. The healing is found in the narrative shift, but also in ritualized ancestral memory. The descendants of the Syphilis Study participants were unified through a common memory experience; and by forming an organization to honor their fathers they began a signifying practice reflective of an evolution in family perspective. This journey from trauma narrative to healing narrative is consistent with the constructs posited by Joy Degruy Leary, internationally acclaimed social work research scholar, and author of Post-Traumatic Slave Syndrome: America’s Legacy of Enduring Injury and Healing (Degruy-Leary, 2005).
Post-Traumatic Slave Syndrome

If a group’s self-naming is rooted in a traumatic experience, is the impact transmitted across generations? Joy DeGruy Leary answers this question with a resounding, “yes.” Her post-traumatic slave syndrome theory suggests that the psycho-social aftermath of trauma has been transmitted to African Americans through the family, the community, and society at large through socialization processes that have resulted in an “assault on the collective psyche of the group” (DeGruy Leary, 2003).

The following narrative account of a case of mental or emotional imbalance linked to the generational transmission of “post traumatic slave syndrome” offers an example of such. In this case, a troubled ancestral spirit is identified as the source of a client’s mental and emotional disturbances. A discussion of African American experiences of historical trauma and questions regarding the curative properties of selected cultural practices follows the analysis of this case study.

Embracing an expansive definition of family suggests that the human quest for ire (a Yorúbá term translated as blessings, prosperity, love, healing, wholeness, and wellbeing) spans generations and calls into question how we negotiate time, space, and spirit on both individual and communal levels. Oral historian Claude Fergus reports that in his research work on oral traditions related to the Atlantic Slave Trade in Africa, two informants belonging to the 5th and 6th generations removed from an ancestor who was kidnapped and sold into slavery in the mid 1800’s, told him this story:

_in the early 1980’s Florence’s daughter, Francine, was a student at a French University, when she suddenly began to demonstrate strange behavior akin to mental derangement or drug addiction. French doctors failed to determine the cause and she was taken back to Togo to undergo various conventional (Western) medical tests, to no avail. As a last resort, Florence’s father consulted a diviner who enquired whether any of his ancestors had suffered enslavement. To Florence’s knowledge none had. Nonetheless, the diviner assured Florence that her daughter’s affliction was the result of the return of an enslaved ancestor, and that a remedy could only be effected through appropriate appeasement of the ancestral spirit. …Florence then confronted her mother, a direct descendent of Agbesi. …Reluctantly her mother related the story of Agbesi’s kidnapping. Though she was sold into domestic slavery, she was not shipped off, but instead was purchased by a wealthy Anglo woman who incorporated her into her family and the secret society of the wealthy.

On the advice of the diviners, Florence established a shrine on her compound and prepared for an elaborate feast in atonement of the aggrieved spirit. Every detail of the feast was strictly in accordance with the instructions given by the diviners. The feast lasted for several days. After the first feast, Francine made a remarkable recovery. …Florence’s elder sister was similarly afflicted, but refused to consult the diviners, pleading that her Christian faith frowned on such practices. She did not recover and she passed away. The devotees and supporters of the shrine site Florence’s sister’s death as … evidence that only traditional divination and appeasement feasts could keep the descendants of Agbesi clinically safe and sound of mind (Fergus, 2009).

The narrative coaching theoretical construct in an analysis of this story sheds the narrative evolution. The story starts with the recognition that something is wrong. Francine, a student at a French University began to experience symptoms akin to mental disorder and contacted her mother, Florence. This is phase one, situate. The second phase, search, began immediately as Florence contacted medical doctors, and eventually a traditional diviner in search of treatment for her daughter. The western trained medical doctors were perplexed by Francine’s case. The traditional diviner/healer asked a pivotal moment question, “Is there a history of enslavement in the family?” This question moves the narrative to stage three, shift, where the search is re-directed. Upon further investigation, Florence discovers the story of Agbesi’s kidnapping and subsequent sale as a slave. With this knowledge, the diviner offered a healing narrative, complete with diagnosis and prescriptive treatment, ritualized ancestral memory. The narrative then moves to stage four, sustain. Florence and her daughter followed the prescription, organizing festival activities and establishing an ancestral shrine. Francine experiences a remarkable recovery and the healing narrative emerges.

Fergus cites this narrative as a good example of the role of oral tradition in the reconstruction of ethno-history and the validation of kinship ties in West Africa. I examine it as an illustration of narrative analysis in studying the evolution of a family narrative from trauma to healing. Francine, in this case report, is six generations removed from the enslaved ancestor, Agbesi, whose troubled spirit, according to the Ifa diviners, caused mental and emotional disturbances. Several factors are notable:

1) The epistemological value of oral traditions - Ferguson uncovered Francine’s story through his fieldwork in Africa collecting oral narratives related to the Atlantic Slave Trade. He uncovered both a family history and a therapeutic strategy.

2) The generational impact of cultural trauma - how one negotiates time, space, and spirit in a quest for a deeper understanding of the biological, psychological, social and spiritual factors impacting wellness is highlighted in Francine’s narrative.

3) The curative properties and therapeutic value of ritualized ancestral memory - In Francine’s case, her mother’s willingness to follow the directive of the traditional diviner/healers to establish a consecrated ancestral altar and provide an elaborate celebration for the appeasement of the Agbesi spirit, reportedly saved her life.

Cultural Traditions and Healing Narratives

Where might we uncover opportunities to embrace cultural traditions that carry healing properties within them? Could the movement to value black life benefit from an exploration of oral traditions that excavate ancestral strategies for survival and wellbeing, even in the context of a DNA carrying the impact of historical trauma? Could it be that African and African American cultural traditions carry not only narratives of trauma, but also strategies for healing?

In his use of cultural trauma theory to explore the formation of an African American identity, sociologist Ron Eyerman points out that the collective memory of slavery as a historical trauma that grounds a people’s sense of self carries with it a generational impact (Eyerman, 2001). Case in point, I recently overheard an African American undergraduate student talking to her psychology professor about a paper she was working on. She said “If all you see in the history books is about your people as slaves, I think it has to have some impact on you. I don’t know how to write about that.” The professor asked her to come see him in his office. I walked on by wondering how many African American students for how many generations have wrestled
with that idea, acknowledging that the very identity of African Americans grows out of a cultural memory associated with trauma. And yet in the case of Francine, as described by Fergus, the associated trauma goes beyond a constructed memory and is seated in the psychic/emotional realm. Research scholars at the University of Minnesota Extension’s program on Historical Trauma and Cultural Healing argue that historical trauma, “shared by communities, can result in cumulative emotional and psychological wounds that are carried across generations,” effecting the mental and physical well-being of entire communities, and threatening the vibrancy of entire cultures (University of Minnesota web retrieval, 2016).

What is the antidote for historical trauma? In the case cited above, the antidote was ritualized ancestral memory. The University of Minnesota’s program also advocates cultural healing, based on the philosophy that there is therapeutic value in re-connecting to indigenous cultural values and excavating strategies for healing. The Yoruba scholar Rowland Abiodun tells us that the artist is the first to speak. In Yoruba mythology, he says, it was Ela the Orisha who spoke through the verbal, the visual, and the performing arts, communicating wisdom and elevating the consciousness of the people.

Take, for example, the film Sankofa, released in the early 90’s. It is a film about cultural memory. The sankofa bird, with its feet planted forward and its head turned back is the bird of passage, looking back before moving forward. Following the release of the film, Sankofa study groups, mentoring groups, bookstores, and businesses could be found throughout the country. People everywhere were focusing on their historical roots. The question they asked then is still relevant today. “Can we Sankofa?” Can we go back in our autobiographical and our cultural memory and fetch something of therapeutic value and inspiration, something from which to fashion a new story for the future? Can we find therapeutic value in what has been forgotten, the non-western worldview of family kinship ties that extend backward and forward at the same time?

Developmental psychologists suggest that autobiographical memory provides a sense of grounding for the individual, a sense of coherence and personal identity. Stories tell us who we are, they say. A team of psychologists, led by Robin Fivush from Emory University’s Center for Myth and Ritual in American Life asked this question to explore the significance of family history in adolescent identity and well-being. They used an instrument called the “Do You Know” Scale and the findings indicated that adolescents who knew more about their family history displayed higher levels of emotional well-being and higher levels of identity achievement (Fivush, et. al, 2011). Our personal stories are embedded within our family stories and within our cultural stories. How do we remember? How do we Sankofa? Why Sankofa?

In pondering these questions, I have turned to womanist scholars Emile Townes, Carol Duncan, Diane Stewart, and Linda Thomas. In her popular essay, “Vanishing into Limbo, the Peculiar Career of Aunt Jamima,” Townes speaks of turning to “natural memories” as a means of constructing images that can counter those of society that tend to deform and disfigure Black personhood (Townes, 2006). Carol Duncan, in her ethnomusicographic study of Auntie Jemima in Caribbean religious culture speaks of how, through her own reflections and interviews with women in the Spiritual Baptist Church in Toronto Canada, she came to understand how the same characteristics associated with negative images of Black Motherhood had been “re-worked and re-invented in the religious lives of individual women to provide an empowering image of black motherhood, contrary to the servility implied by the stereotype” (Duncan, 2011). Diane Stewart, likewise, speaks of seeing with new eyes. In her essay, “Dancing Limbo: Black Passages through the Boundaries of Place, Race, Class, and Religion,” she reports that she turned to her father’s natural memories of the limbo dance and thus experienced a healing of some of the most gaping wounds scarifying her spirit (Stewart, 2006).

Anthropologist and womanist theologian, Linda Thomas, encourages us to excavate the narratives, to conduct ethnographic fieldwork documenting the direct speech of poor and working class black women in our efforts to advance a liberative praxis that will allow us to construct new knowledge that foregrounds the experiential voices of black women (Thomas, 1998). Embracing oral traditions offers a set of practices, strategies, and techniques for healing the past and creating the future, a set of practices that allow us to experience higher levels of emotional well-being and higher levels of generativity, demonstrating care and concern for future generations. Just as Alex Haley began with fragments and scraps of stories from the elders in his family who sat on the front porch of his Henning, Tennessee home and ultimately created the saga of a people; likewise, every person’s story has a larger meaning.

Alex Haley, by sharing his personal narrative and heritage story, inspired countless African Americans to excavate their ancestral stories, to discover and honor unknown parts of themselves. In the Yoruba tradition, one way that ancestors are honored is by the chanting of oriki. The term oriki technically means “to stuff the head.” The oriki is a cultural healing strategy. It is a technology where words of praise are concentrated and verbally hailed to alter an existing state of being. In her study of oriki as chanted in Ilé, Nigeria, Karin Barber concluded that in the chanting of oriki, “the past is translated into the present as great men and women of the past are called on to be present in the affairs of their descendants and to lend them some transmitted glory.” The oriki, she says, “Opens channels between beings through which powers can pass and potentials emerge.” (Barber, 1993)

Like Barber, Babalowo and scholar of African religions, Kolá Abimbola also examines cultural traditions for healing strategies. Turning to the sacred Ifa literature he sites this story from Ifa scripture Odu Idisogun:

There was a time when there was a fierce warrior named Bembe. Bembe is also the name of a musical instrument, a drum. The warrior Bembe had been fighting for many years and one day decided that he wanted to go and conquer Nope, a city of great warriors in North Central Nigeria. As is customary in Yoruba culture, whenever one has an important decision to make they go to the Ifa priest for divination, so Bembe went for divination. The diviners told him that instead of going to wage war he should go to the city and make music. They said he would conquer the people by using the power of music. Now the King of Nope also went for divination about the same time. The diviners told him that someone was coming to wage war on the city and he should offer sacrifices. “Some being coming to conquer us? No way! We are a city of great warriors. Even our children are born as warriors. They ignored the diviners and they did not make sacrifices. When Bembe arrived, they were expecting him to come with the implements of war. Instead, he came playing music. The music was so beautiful that all the people came out of the palace and all of the people came out of their houses and started dancing. The people surrendered to Bembe. Music binds people together. It is an important force for social cohesion (Abimbola, 2010).
This Ifá text directs attention to the inherent healing power in sound harmonics. Such power is a consistent thread in African American culture. Likewise, Bernice Johnson Reagan reminds us of the role of sacred music, functioning as scripture with sustaining power for the countless number of African Americans who participated in the great migration, those who left all that they knew to reconstruct their lives in a different place. (Reagan, 2001) Isabel Wilkerson says they were seeking the “warmth of other suns.” Were they not also seeking to heal their trauma narratives and redefine community under new conditions? Wilkerson reported that she chose the title from a footnote in the work of Richard Wright, saying the phrase represented the resolve that some six million Black people showed in leaving a “place that had shunned them for a place they hoped would sustain them.” The family narratives of those six million African Americans who migrated North and West, certainly evolved over time as they created new narratives that would sustain them as they healed their psychic wounds and re-authored their lives. Wilkerson interviewed over 1200 people to find the stories of the three protagonists around whom she constructed the larger story of the great migration, a story of the evolution of family and the quest for emotional emancipation (Wilkerson, 2010).

**Emotional Emancipation Circles**

Another case in which the evolution of family is seen in African American cultural narratives is the Emotional Emancipation Circles Program developed by the Association of Black Psychologists along with the Community Healing Network. The program is built on seven principles, seven keys, and seven actions that lead to emotional emancipation, healing, and wellness. The program defines emotional emancipation as “working together to free ourselves of the lie of Black inferiority and the emotional legacies of enslavement and racism that continue to keep us captive” (Unpublished document, 2015). Emotional Emancipation Circles are described as places where black people can come together to share their stories, deepen their understanding of the psychological impact of their history, and acquire emotional wellness skills.

Here’s an auto-ethnographic account of an introductory EEC in session: A small group of 20 individuals met in a seminar room on the campus of a Historically Black University. Nearly all the participants were African American, males and females, ranging in age from mid-20’s to mid-60’s. One by one the participants introduced themselves, following the instructions to share something about their ancestral lineage. The mood was light and cheerful. Then the facilitator posed the next question, “Why is emotional emancipation important to you?” The first few people answered with the same lighthearted mood. “Emotional emancipation is important to me because I want to live my best life.” “Emotional emancipation is important to me because I don’t want to be held captive anymore. I want to throw off the weight of past experiences so I can be free.” The second, the third, and the fourth person spoke, sharing with sincerity, authenticity and deep emotion. Suddenly it was my turn to speak. My throat chakra shut down. I could not speak. My chest was heavy, but there were no tears. I could only mouth, “I can’t talk.” The facilitator moved on around the room.

The mood in the room changed, became more serious. The first person started over, even her tone reflected an answer from a deeper inner space. She spoke slowly, “Emotional emancipation is important to me today because I don’t want to be held captive anymore. I want to throw off the weight of past experiences so I can be free.” The second, the third, and the fourth person spoke, sharing with sincerity, authenticity and deep emotion. Suddenly it was my turn to speak. My throat chakra shut down. I could not speak. My chest was heavy, but there were no tears. I could only mouth, “I can’t talk.” The facilitator moved on around the room.

Everyone spoke with the same level of self-disclosure, honesty and sincerity. The facilitator looked at me. I simply shook my head. I still could not speak, but there were no tears. The facilitator showed a touching power point of images and words reflecting moments of emotional pain within a history of struggle and survival. She reviewed the seven Egyptian principles of Maat: Truth, Justice, Correctness, Harmony, Balance, Reciprocity, Order. Noting that these were the principles that guided our ancient African ancestors and these would be the practice of these principles that would hold the key for Black people to free themselves from “the lie of Black inferiority and the emotional legacies of enslavement and racism.” (EEC unpublished document distributed, 2014).

She reviewed the seven principles of emotional emancipation: 1) Being Truthful. 2) Being justice. 3) Acting with Correctness. 4) Living in Harmony. 5) Living in Balance. And the seven daily practices: 1) Love and respect. 2) Patience and perseverance. 3) Managing thoughts, feelings, and actions. 4) Interdependence. 5) Self-discipline and sacrifice. 6) Unconditional love. 7) Cooperation to foster strength. (EEC unpublished document, distributed, 2014). She emphasized the importance of healing old wounds to better the lives of black people everywhere. She asked us to spread the message and to be a part of the healing network. At this point I raised my hand and said, “I can speak now.” With a look of relief, she nodded. “I need to be emotionally free,” I said, “Because I experienced a deep personal trauma about a year ago, I lost my son to suicide. I have dry tears and those are the worst kind, because there is no release. The dry tears muted my voice. It is not that I try not to shed tears. It is really that the tears just don’t come.” The facilitator listened quietly and the other participants clapped with relief. When the session was over, one woman came up to me and said, “When you know you have survived, the tears will come. Right now, you are protecting yourself because you don’t know for sure that you could handle the emotional release. When you are ready, the tears will come.” Within the two -hour time span of the circle gathering, I experienced a therapeutic narrative movement. I remember thinking, “So this is what the Emotional Emancipation Circle is all about.” It is an intentional narrative movement through a time/space memory toward a place of healing and wholeness.

A mapping of the narrative movement, as illustrated above, using Michael White’s model of narrative practice highlights the use of what he refers to as externalizing conversations (White, 2007). While this concept emerges from White’s body of work as a family therapist, it has implications for the individual and group practices facilitated and encouraged by the Association of Black Psychologists and the Community Healing Network through Emotional Emancipation Circles. White notes that many of the people who seek therapy believe that the problems in their lives are associated with their own identity or the identity of others. Externalizing conversations help re-direct the focus from the person to the problem. “The problem is the problem,” he says, “not the person.” The internalization of the problem exacerbates the problem, and in fact, the habits of thought that reinforce the problem are cultural in origin. Acknowledging Michel Foucault’s contribution to our understanding of the cultural phenomenon of “dividing practices” and how these practices reinforce concepts of spoiled identity, (1965, 1973) Emotional Emancipation Circles are, in effect, a prescriptive practice to counter the “spoiled identity” narrative. One on the phrases that is repeated throughout the EEC material is “Defy the lie of Black inferiority.” The stated objective is to help people free themselves of the “emotional legacies of enslavement and racism that continue to keep us captive.” (Unpublished document distributed, 2014). This strategy operates at the
individual as well as the social level, shedding light on movement from narratives that limit to narratives that expand the space for agency and empowerment.

In the words of Michael White, “When the problem becomes an entity that is separate from the person, and when people are not tied to restricting “truths” about their identity and negative “certainties” about their lives, new options for taking action to address the predicaments of their lives become available.” (White, 2007) This does not excuse the person from taking responsibility for addressing the problems they encounter, to the contrary, it creates an alternative narrative source from which they can draw inspiration and bring a new story to life. The narrative practice espoused by the EEC Program helps participants unravel some of the negative conclusions they have internalized, based on the social history of African American people, an identity that by its very name carries with it a history of trauma, as noted in the work of Ron Eyerman, cited earlier in this conversation.

Following Michael White’s narrative mapping schema, we identify another aspect of the externalizing conversation, a movement toward the re-authoring conversation. Through its emphasis on the seven principles, the seven keys, and the seven practices, the EEC program model encourages the re-authoring conversation, one that shifts the self-understanding from the negative stereotypes that have shaped the psyche of Black people in America for centuries. See the litany of statements defining Emotional Emancipation:

- Emotional emancipation is about freedom for Black people – freedom not only in body, but in mind and in spirit as well. It is freedom from any and all toxic ideas about the inferiority of Black people, Black culture, Black intellect, Black hair, Black skin and other physical features. It is freedom to see ourselves as the beautiful, lovable, intelligent, capable, and worthy people we are. It is freedom to see ourselves beyond the negative stereotypes that have burdened and limited us for centuries. It is freedom to participate fully in all aspects of the global village. (EEC Unpublished document, 2014)

- The resistance and liberation metaphors abound here. They represent prescribed action for addressing the social problems that have often been internalized and attached to the self-identity of Black people. The Black Lives Matter Movement is another example of using externalizing conversations to re-shape social identity. Why would it be necessary to build a movement asserting that “Black lives matter”, if the cultural norms and cultural stories did not suggest that Black lives do not matter? Through its high-profile communications strategies in the virtual and the physical market place of ideas and actions the Black Lives Matter Movement seeks to re-author the narrative and send a message to society on a large scale.

Conversations are being held in towns and cities throughout the US in homes, schools, places of worship, town halls and public squares, with the goal of promoting the evolution of a new narrative of connectivity and oneness. Applying Michael White’s model for mapping narrative practices places these activities within the realm of externalizing conversations as well as re-authoring conversations. Though White used these concepts in the context of individual and family therapy, they seem applicable to a larger social context. The desired outcome is movement from the narrative that gives rise to divided practices to the emergence of a cultural narrative that gives rise to unifying practices. According to White, re-authoring conversations encourage people to share stories about their lives, including some of the experiences that are exceptional or out of sync with their dominant story (White, 2007). These moments of exception create openings for the beginning of a re-authoring conversation.

White draws a parallel between the structure of literary texts and the structure of narrative therapy. A similar parallel can be found between individual therapeutic conversations and social/cultural healing conversations. The work of truth, racial healing and transformation commissions have historically included an intentional focus on movement from the historical narrative of racial hierarchy to re-authoring the narrative of human family. White uses the terms “remote history, distant history, recent history, present, and future” to refer to the landscape of identity in the context of individual and family therapy (White, 2007). The Kellogg Foundation’s Guidebook’s section on narrative change and racial healing refers to story-telling and relationship building as a prerequisite for addressing structural change and realizing racial healing. Recognizing that each community has a unique racial history, TRHT guidelines encourage organizers to conduct a racial history assessment that consists of both archival and fieldwork. The assessment includes formal interviews and informal conversations with a diverse group of residents to collect information on housing, education, law enforcement, religious practices and business practices as the initial step to designing sessions for educational externalizing conversations and re-authoring conversations.
White’s concept of “remembering conversations” comes into play here (White, 2007). The term “remembering” is used in the context of associations in life. Remembering conversations provides an opportunity for people to confront dominant identity narratives and revise them for a more expansive, healing perspective. According to White, remembering conversations in a therapeutic context:

1) Evoke life as a membered club and identity as an association
2) Contribute to the development of a multi-voiced sense of identity
3) Open possibilities for the re-vision of one's membership of life
4) Describe the preferred versions of identity
5) Emphasize mutuality
6) Encourage deliberate re-engagement with significant figures

It could be that “remembering conversations” function in similar ways, in the context of public conversations as part of racial healing and transformation work. The personal experience race narrative detailed below illustrates this point: In my ML King Day Celebration speech, I recalled how I became a social researcher at the young age of four because I learned to ask critical questions in my quest to understand what it meant to be “colored.” At the close of the program, a young white woman came up to speak to me. She was excited to share a personal story about how her pre-school child had described her friend (an African American girl) as a creamy chocolate color. She enthusiastically concluded, “We’re making progress. She didn’t see color.” I think what she intended to convey was that her child did not make a friendship judgment based on race. Of course, she saw color. Creamy chocolate is a color, not a race. The point, though, is that narrative dialogue can and does create spaces for movement, even evolution in consciousness and understanding. The ML King Celebration program did not include an opportunity for a Q & A or talk back session. One could only imagine what might have emerged if the opportunity for engagement had been built into the program.

Conclusion

In summary, this paper posits narrative change as a significant component in the evolution of family, especially in the case of an African American identity constructed in the context of the social history of slavery and racial hierarchy in America. Attention and intention can go a long way in moving from a trauma narrative to a healing narrative in seeking to enhance health and wellness and the quality of life for all people. Remembering the life and legacy of the 600 Black men who participated in the Public Health Syphilis Study without informed consent, points to the base line narrative underlying the study as one that de-valued Black life. This recognition alone, lends credibility to narrative change as an important part of the agenda for global health, wholeness, and wellbeing.

References


Voices for Our Fathers:
Family in Community Engaged Healing

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Author Note
This article is an account of the community-based efforts taken to achieve healing among
descendants of the men involved in the United States Public Health Syphilis Study at Tuskegee.
The authors have no conflicts of interest.

Abstract
The Voices for Our Fathers Legacy Foundation is an organization developed and administered
by descendants of the participants in the United States Public Health Service Syphilis Study
at Tuskegee. The Foundation works in partnership with the National Center for Bioethics
in Research and Health Care to address the intergenerational impact of the USPHS Syphilis
on descendent family members and the family-community more broadly; and to build public
awareness around issues of social justice and bioethics as it relates to public health. This work
discusses the steps the Foundation and the Bioethics Center have taken in the healing process
as a community and family unit. The Foundation’s community healing process emerged out
of being able to recognize the problem, to build awareness and develop steps towards action
through preplanning and preparation, and to stabilize or implement the action steps through
community-based events.

Keywords: Community healing, community engagement, bioethics, public health, social justice,
USPHS Syphilis Study at Tuskegee, family
**Introduction**

The Voices for Our Fathers Legacy Foundation (VOFLF), an organization developed and administered by descendant families of the participants in the United States Public Health Service Syphilis Study in Tuskegee (henceforth, the Study) has an ongoing partnership with The National Center for Bioethics in Research and Health Care (NCBRH). The purpose of the partnership is:

- to broaden the spheres of ethics to fully reflect the work that must be done to better inform the public on the risks and benefits of human subject research for vulnerable populations, particularly African Americans. Descendant family members are transforming the national tragedy of the U.S. Public Health Service Syphilis Study at Tuskegee to a journey of community engagement, beneficence, and social justice.
  
  (Warren, 2014a, p.8)

In addition to social justice, Ms. Lillie Head, a descendant family member and chair of the Leadership Team for the VOFLF, stresses the importance of their work with NCBRH as an effort to build awareness about the true histories of the men involved and to reclaim their narratives. Ms. Head (2013) stated:

> The 623 African American men living in Tuskegee and Macon County, Alabama from 1932-1972 were unaware they were being abused. They were participating in the infamous study that was conducted by the United States Public Health Service. Today, most of what we read or have seen about these men does not tell their life stories or mirror them with a positive image. In spite of the crippling physical, social, and emotional affects suffered by them and their families, they survived. We do not know how they survived these perils. Only by learning their stories, will we begin to understand the miracles of their lives. When we become familiar with all of their personal stories, will we be made aware of their strong character and their steadfast faith. We will learn of their kindness, and appreciate their paternal guidance that helped to shape and will continue to influence future generations. We will know of their kindness and how they cared for their neighbors. We will learn they owned land, farms and homes. We will be inspired by how they provided for their families, became self-employed and worked for the federal and local governments. We will come to admire their quests for better lifestyles and economic opportunities by migrating to northern cities. And by learning their stories, we will acknowledge that they have contributed significantly to their families, communities, country and yes, the world. Our fathers were amazing survivors: their stories are powerful and must be told. We, their families, in partnership with the National Center for Bioethics in Research and Health Care will make sure that history records their stories. (p. 1)

The impact of the USPHS Syphilis Study extends beyond the abuse of the men who were survivors of the Study. Anger at the abuse and social injustice the men suffered haunts family members across generations. This work discusses the steps the VOFLF and NCBRH have taken in the healing process as a community and family unit. The VOFLF community healing process emerged out of being able to recognize the problem, build awareness and develop steps towards action through preplanning and preparation, and stabilize or implement the action steps through community events. These stages are typical of the cycle of community readiness for change and healing (Thornton, 2000).

**The Importance of Family as Community**

The survivors of the USPHS Syphilis Study and their descendants form a family-community that is united by the experience of the Study. Family is the basic social unit of any society. What constitutes family varies within and between societies, and the concept of family is important in understanding the depth of the effects of the Study not only for descendant family members but for the family-community more broadly.

In the United States the ideal family unit consists of a mother, a father, and their children (nuclear family). However, family takes on many different forms, e.g., single headed households with either the mother or the father as head of the home, blended families with a husband and wife and the children from previous marriages, or extended families with multiple generations living together. Family can also take on different meanings depending on the context in which it is used.

Societies have ways of extending family by creating non-biological kinship bonds (fictive kin) to augment biologically related family. Due, in part, to the high mobility of people in today’s modern society, it is not uncommon that special family-type bonds are formed with friends and use of kinship terms such as (play) sister and (play) brother are used. Children usually refer to the friends of their parents as aunt and uncle (Liebow, 1967; Stack, 1974). These people are in some cases closer than actual biological kin and with whom reciprocity is expected.

The fictive kinship boundaries can also be extended to sororities and fraternities as well as community organizations such as churches, the Masons, Kiwanis, Lions Club, Moose, and Veterans, among others. Members of these social organizations are committed to support not only the members of their local group but the larger community family including national and international members. Regardless of the level, the term family carries certain expectations of identity, obligation, and unity.

The term Tuskegee family can include all those associated through schooling and/or work with the University. It can also refer to all those who have spent all or part of their lives in the geographical area identified as Tuskegee, Alabama. A person who once lived in Tuskegee, but subsequently moved out, may still identify with being a member of the Tuskegee family. Events that take place, whether positive (the Tuskegee Airmen) or negative (the United States Public Health Service Syphilis Study at Tuskegee) affect all who are associated with the name Tuskegee.

**Recognition and Preplanning/Preparation: Steps towards Community Healing**

**Recognition and Awareness**

At the national level, recognition of the Study and the government’s role in a horrific experiment (allowed to continue for 40 years) was addressed in 1997 when President William Jefferson Clinton “apologized to the men who were involved in the U.S. Health Syphilis Study at Tuskegee, their families, the African American community, and the Nation for the longest non-therapeutic research study in U.S. history” (Warren, 2013a, p. 8). As part of the apology, the government provided funding for the establishment of the NCBRH at Tuskegee University.
in 1999. The mission of the Center is to work towards preventing any reoccurrence of unethical research in the future, to continue to honor the legacy of the men and families of the Tuskegee Study, and to address “...the tremendous sacrifice that the men and their families have made toward improving human subject research and health care delivery” (Warren, 2013a, p. 8).

In 2006, descendants met to begin the process of healing and to seek answers as to how the Study could have taken place and been allowed to last for 40 years. The focus of the meetings was “…to tell their fathers’ stories and honor their legacy” (Head, 2015a, p. 2). It was recognized that only the families themselves could tell the stories of their fathers. Work with the National Bioethics Center was undertaken to address issues about how to protect vulnerable populations from abuse in research.

Additionally, an Annual Celebration of the Presidential Apology has been held every year. Beginning in 1999, the Celebration has been held at the National Bioethics Center in Research and Health Care. In 2010 the name for the annual program held for the National Apology was changed from Celebration to Commemoration, which the families felt was more appropriate. The descendant families, who attended the Annual Commemoration of the Presidential Apology, expressed gratitude for the opportunity to celebrate the National Apology, but they wanted to augment the reason for the Commemoration. Families wanted to find ways to serve and help bring out more positive and personal outcomes to the legacy of the Study.

Preplanning and Preparation

At the 2011 Annual Commemoration Service of the Presidential Apology, three individuals, who were descendants of the families, were selected to represent the families in dialogue with Dr. Rueben Warren, Director of the NCBRH and others parties involved in the planning of the Annual Commemoration Services, the luncheon, and the role of descendants in the Service.

A conference call with Dr. Rueben Warren focused on identifying issues related to research, education, and service for the families, who were impacted by the Syphilis Study at Tuskegee. Three areas of concern were identified: 1) to determine how descendants and the NCBRH could work together towards healing, 2) to address family concerns about the stigma families were experiencing because of the Study, and 3) to establish a process that would allow the families to honor their fathers and their legacy.

Three concerns were discussed regarding the healing process and resources needed. These concerns included: 1) the need to continue the healing process initiated at 2011 Commemoration Service, 2) to begin the process of healing by addressing how the participation of the men in the Study had affected and continued to affect the lives of the families, and 3) to begin the process of seeking help through contributions from other foundations and/or entities.

Finally, in 2011, the following goals were set by descendant family members: 1) to establish a vision statement for the Foundation, 2) to establish a 501C3 status for the Foundation, 3) to award scholarships to members of descendant families’ members for education, 4) to address how the Bioethics Center would be involved, 5) to increase member tributes to the men, 6) to set up a leadership group, and 7) to set up committees (Julkes, 2012, p. 1).

Year 2011: Healing Session

As part of the Annual Commemoration, descendant families participated in the first closed Healing Session. The purpose of the session was intended to address three questions: “What does healing mean? What does healing look like? Why is healing so important after so many years?” (Wimberly, 2012, p. 3).

The first family healing session was led by Drs. Edward and Anne Wimberly. The session dealt with the stigmatization that the descendants and the families felt because of the Study and "each member started by voicing their concerns and distrust with all aspects of the study. This indeed was an emotional session for all family members present” (Wimberly & Wimberly, 2014, p. 6). Family members were able to:

...share(d) stories about how the USPHSSS had impacted the lives of Our Fathers and Our Families. We shared ways by which we were bringing about healing personally – sharing little things and projects that each had done or were doing to remember and honor our fathers or grandfathers were most inspiring...and considering ourselves, the descendants, not victims but survivors and victors. We felt encouraged to become more determined to uplift our Fathers’ legacies and transform the legacy of the USPHSSS rather than remain bitter and do nothing to bring about change. (L. Head, personal communication, 2016)

Year 2012: Leadership building, the Public Health Ethics Intensive, and Recalling of Family Stories

In 2012, a leadership team consisting of family members was formed and the group took the name Voices for Our Fathers. In addition, the first Voice for Our Fathers Newsletter was published. The leadership team also worked in conjunction with Dr. Warren and the NCBRH to offer the first Public Health Ethics Intensive course, The True Legacy of the USPHS Syphilis Study at Tuskegee, as part of the Annual Commemoration. The focus of the course was to celebrate the men in the study, recall their stories, and identify positive outcomes. At the same time, “the course provided rigorous training for students, faculty, practitioners, and community members to build capacity and competency in public health ethics, bioethics, and research ethics” (Wilson, 2013, p.7).

Year 2012 also marked the second meeting of the Family Healing Sessions. The goal of the second Family Healing Session was for members of descendant families to recall their family stories. Dr. Wimberly pointed out that healing meant different things to the family members. Participants found it as a way to answer “burning questions” about the Study. For others, it was being able to talk about what happened without fear of shame and stigma. Some needed a safe place to talk about memories that included sharing family memorabilia and family rituals. Yet others “needed a safe place to complain and lament to God why such a horrible experiment took place” (Wimberly, 2012, p. 3). Still others were looking for financial accountability in terms of how money given to the men and their descendants was spent, and what were the tangible benefits available for the children of the descendants.
Many descendants expressed joy at being able to share their experiences and stories. Having a space and platform in which to share their feelings was able to "contribute to their own healing as well as the healing of others" (Wimberly, 2012, p. 3). The descendants better understood the power in recalling and telling their stories related to the Syphilis Study "by seeking positive plots and outcomes despite the negatives of the study" (Wimberly & Wimberly, 2014, p. 6).

Year 2013: Strategic Planning and the Importance of Resilience in Healing

The 2013 Commemoration events included a Family Healing Session, the 2nd Annual Public Health Ethics Intensive Course, two special sessions on youth violence prevention for the Macon County Public School children and youth, and the Annual Luncheon and Banquet honoring the legacy of the men in the Syphilis Study and their families.

During the 2013 Commemoration meeting, the leadership team addressed the need for: 1) a vision/mission statement, 2) establishing a family scholarship fund, 3) the development of the “Living Memorial and Inspirational Garden” granted to the families by Tuskegee University and the National Center for Bioethics for Research and Health Care, and 4) how the families could have more of a voice in the upcoming Commemorative Programs. Voices for Our Fathers Legacy Foundation also proposed a five-year Strategic Plan for 2014-2019. The plan included six projects:

1. National Bioethics Center Advisory Board Representation - to ensure the voice of the families was represented and information relayed to families.
2. Education for Clinical and Public Health Researchers and Practitioners – to develop online programming and a video documentary on the Study from a family perspective and to conduct presentations at national meetings.
3. Preserving the History – to identify a commissioned artist to construct a monument or garden at the National Bioethics Center and to seek support and to encourage exhibits at museums nationwide.
4. Convening Study Families – to develop a social media presence for family members to develop and disseminate family newsletter and secure a funder
5. Scholarship – to establish a scholarship for family members/descendants studying nursing, medicine, public health, social justice law, science; to establish a scholarship for graduate students with a special interest in bioethics, public health, and medicine.
6. Organizational TO DOs – establish VOFLF as a 501C3; accept donations from family members; identify and work with fundraising consultants; convene quarterly meetings of the Legacy Committee and bi-monthly meetings for committee chairs; and develop a budget (Wiggans, 2013, p. 6).

In 2013, the theme of the Public Health Ethics Intensive Course was Women, Ethics and Social Justice (Warren, 2013, p. 8). There has, and continues to be, attention centered on the men who were in the USPHS Syphilis Study. However, these men were a part of families that included women and children; wives, sisters, daughters and granddaughters, nieces, other women and girls. The course focused on these forgotten women (R. Warren, personal communication, 2016). In addition to the course, families held the third Family Healing Session titled Forgiveness and Healing. Family members reflected upon words from President Clinton’s Apology, “…only you have the power to forgive” (Wimberly & Wimberly, 2014, p. 6). Moreover, family members stated that they:

...learned and shared strategic ideas and activities that will help us to live above the infamous study. This year we explored different models of forgiveness that included the discernment model, which shows God at work transforming wounds into scabs, and the discovery model which reveals the discovery of forgiveness when we realize that we share similar hurt and pain (Wimberly & Wimberly, 2014, p. 6).

The focus was on resilient practices "that the descendants had learned that enabled them to keep on keeping on despite the negative circumstances" (Wimberly & Wimberly, 2015, p. 4). Wimberly (2013) describes resiliency for the families as strategic activities that:

...help them come to grips with difficult situations in life. These practices help families find meaningful ways to deal with the meaninglessness of life in creative ways. It is learning to manage life’s difficulties despite major obstacles. Families learn to handle difficult problems through meaningful practices that keep them going on despite life’s difficulties. In short, through a process of recalling our own stories’ as descendants of the United States Public Health Syphilis Study at Tuskegee we will identify resilient practices that will help us continue to live meaningful lives.

The practices that will be identified include the practice of unmasking, which is allowing the stories of our lives to come to life in the present. Second, there is the practice of inviting catharsis or allowing feelings to surface in a safe environment. The third practice is relating empathically to others. This means that participants attend to the feelings of others as they emerge and demonstrate care and love. Fourth, in unpacking stories, we are attempting to derive meaning from them. One such method is called re-authoring or editing stories so that they have a healing impact on our lives. In short, resilient practices are those activities of telling our stories that help us to move forward toward meaningful and purposeful lives. (p. 2)

After the meeting, a memorial service and the lighting of six candles in honor of the men was held.

Year 2014: Action Steps for Leadership, Social Justice, and Models of Forgiveness

During the 2014 meeting of the leadership team the following steps were taken:

1. The mission statement for VOFLF was accepted, by-laws were prepared, and Voices for Our Fathers was officially registered as an organized group in the State of Alabama.
2. The process was initiated to establish Voices for Our Fathers Legacy Foundation as a 501C3.
3. A five-year structured strategic plan was accepted. The goals of the five-year plan were: 1) to regularly publish a newsletter that will include stories of the men, 2) to continue...
the Public Health Ethics Intensive Course and Healing Event as an annual event, 3) to hold an Annual Commemorative Banquet and Luncheon, 4) to establish a family scholarship, and 5) to build a living memorial and inspirational garden on land made available across from the Bioethics Center on Tuskegee University campus.

4. Established a bank account for the Foundation.

5. Held the Fourth Annual Candlelight Memorial Service after the yearly Healing Session, and families met and planted the first tree, a crepe myrtle, at the Memorial Garden.

6. Agreed that the leadership team meet via quarterly conference calls and to teleconference with Dr. Reuben Warren and Rev. Joan Harrell to discuss progress on related work and goals.

7. Dr. Harrell, Ms. Carmen Head, and Ms. Lillie Head met with Diverse Magazine to discuss the publication of an article. (Head, 2015a, p. 2)

The 2014 theme of the Public Health Ethics Intensive Course and the Healing Event was Ethics and Social Justice. Dr. Warren (2014a) described the importance of these in relation to the descendant families and the National Center for Bioethics:

As Director of the Bioethics Center, I know that a full and committed partnership is a dynamic process that requires constant reflection, review and adjustment. It also requires trust and trustworthiness, which are undergirded by principles of ethics and justice. Because the partnership is based on the relationship between two groups (the Bioethics Center faculty and staff and the descendant families’ members) our effort must assure bioethics and public health ethics are sustained. The fundamental principle of bioethics focuses on autonomy (individual autonomy), beneficence (do good) and justice (fairness and equality). However, principles of public health ethics demand that, in addition to bioethics, we must focus on the group, in this instance, the descendant family members, social beneficence (population good) and social justice (public health).

The African American men who were violated in the U.S. Public Health Service Syphilis Study at Tuskegee made a tremendous sacrifice and they suffered. We are proud and applaud their sacrifice, but we detest their suffering. Sacrifice and suffering are often assumed to be synonymous, but they are not. Suffering is imposed by others. On the other hand, sacrifice is generally an individual decision within one’s locus of control. Sacrifice may require suffering but suffering is not automatic. I am, and I hope, that the Bioethics Center faculty and staff are committed to sacrifice, to honor the ‘Voices for Our Fathers’. It is my responsibility, as Director of the Bioethics Center, to assure that my colleagues do not suffer because of their sacrifice. The men in the Syphilis Study and their family members sacrificed and suffered. The partnership between the descendant family members and the Bioethics Center faculty and staff demands that neither group suffers, but also demands that both groups sacrifice. I am convinced that we will. (p. 8)

The focus of the Family Healing Session in 2014 was Models of Forgiveness. Concerns arose as the descendants reflected on how they learned to forgive the injustices their men suffered and to find meaning and discern spiritual insights through the family stories. The family healing service explored forgiveness as a process unique to humans of being able to turn things intended for evil into good. Drs. Wimberly and Wimberly (2013) focused on the concept of the wounded healer. The premise of the wounded healer is that:

...[T]he spiritual power of God enters our lives and transforms our wounds into scabs. These scabs become sources out of which we care for others. Examples of this are that some children and grandchildren of the men in the study have chosen careers and professions shaped by what they experienced and hear about the syphilis study. Some have entered the medical, educational, and religious fields and some have chosen vocations and avocations of writing in the communication professions.

The Healing Session also focused on recovering the stories growing out of the wounds family members related to the memories of the Syphilis Study and seeing how something positive comes out of the storytelling. The purpose of the storytelling was to make both individual and collective lives more meaningful. (p. 5)

As part of the Family Meeting, family members visited the graves of ten of their fathers and grandfathers and placed a rose on their tombstones. The families also visited the Legacy Museum and the Tuskegee University Archives, where families had the opportunity to see the numerous files of research on the Tuskegee Syphilis Study donated by Dr. Susan Reverby (Head, 2015a, p. 2).

Year 2015: Article Submission, Goal Setting and Progress Made in Family Healing

Ms. Lillie Head submitted an article about the mission of the Foundation to Dr. Joan Harrell, who included the article on the Bioethics Center website. Ms. Head and Dr. Warren also met with Dr. Arvilla Payne-Jackson at Howard University to discuss the VOFLF Foundation’s goals of authoring and publishing the families’ untold stories.

The VOFLF Foundation further proposed to:

...echo the voices of Our Fathers in ways that celebrate their lives, remember their sacrifices, and tell their stories of pain, suffering and survivorship. They were indeed unsung heroes and their untold life stories are rising to be included in the narratives of medical and bio-ethical research and procedures. (Head, 2015b, p. 2)

Dr. Harrell met with Mrs. Catherin A. Morris, Staff Writer at Diverse Magazine, to discuss the possibility of publishing an article.

Other activities included the planting of a rose bush alongside the crepe myrtle in the dedicated Memorial and Inspirations Garden on the grounds of Tuskegee University, and the setting of four goals for the coming year including:

1. Increase the number of descendants attending the 1997 Presidential Apology Annual Commemoration.
2. Continue to publish the bi-annual Voices for Our Fathers Newsletter.
3. Establish a membership organization for descendants and supporters.
4. File for Federal Tax exempt status. (Head, 2015b, p.2)

The Public Health Ethics Intensive Course in 2015 centered on Ethics across Generations. Dr. Warren (2014b) stated the goal for the course was:

...to assure that the generations to come, are fully cognizant of the sacrifices and the triumph of the men in the Syphilis Study. For these men and their families are the prototypes of many women and men who work to improve the human condition, particularly for people of color. The men were depicted as poor and uneducated. Yet we know that is not the full story...They were characterized as victims. Yet, many of the men survived, their legacy lives on and generations to come will honor them as heroes. They were not only victims, they were survivors, these men and their wives are our heroes. (p. 8)

The Healing Event focused on Seeing, Naming and Claiming Identity and Community. The Healing Session was an attempt to:

...to look at the previous four sessions and to assess to what extent the healing of the family descendants had progressed. The assessment dimensions included awareness of dis-membership when it had taken place. For example, dis-membership dealt with how the study disrupted the sense of positive relationships within the family. The second dimension focused on the concept of re-membership, and this related to how positive relationships and respect were restored for family descendants. (Wimberly & Wimberly, 2015, p. 4)

Families realized first that:

...specific resilient practices promoted the ability of the descendant families to 'keep on keeping on'. Second, models related to forgiveness were explored, particularly as the result of President Clinton's apology and the establishment of the Bioethics Center at Tuskegee University. Indeed, President Clinton's apology to the participants and their families certainly was one key factor for the survivors of the study and their family members and descendants.

One of the main exercises undertaken by the family descendants in the 2015 conference was for the participants to draw literally their own eyes and tell what the eyes see looking back over the years since the Study. The key concern was for the family descendants to see themselves now and how different it has become since the time of the Study up to the end of the five years of participating in healing sessions. (Wimberly & Wimberly, 2015, p. 4)

Some of the drawn eyes identified included:

1. Widened Eyes – eyes that are larger than life seeing anew the stark reality of the atrocity of the Study;
2. Squinting eyes – eyes that look as though they are piercing glances into the personal stories that are too difficult to imagine;

3. Double or multiple sets of eyes that reflect the many dimensions of single stories; and
4. Many forms of eyes becoming the means of remembering and retelling the stories that have already been told, but telling newly recalled stories, and their impact on what is happening in current life. (Wimberly & Wimberly, 2015, p. 4)

As part of the Healing Event families visited the graves of ten men from the study at the Shiloh Baptist Church. Families placed flowers and flags on the selected graves.

**Year 2016: Project Development, Honoring the Concept of Family, and a Visit to the CDC**

The National Bioethics Center in partnership with the descendant family leadership in collaboration with Dr. Payne-Jackson from Howard University and Dr. Ajeenah Haynes from New York Medical College are developing a mixed-method strategy to better understand the impact of the Syphilis Study on descendant family members, residents of the Tuskegee, Macon County and beyond. The project is unique because it will involve family members from the beginning and throughout the entire project.

Other accomplishments noted for this year included confirmation of the 501C3 status of VOFLF and the design of a beautiful legacy crest for the VOFLF Foundation by Leo Ware. Goals set for the year were:

1. Descendants to provide interviews to tell the stories of their families.
2. Articles to be written for ethical journals.
3. Meetings of the leadership group to continue on a regular basis.
4. Publication of the bi-annual newsletter. (L. Head, personal communication, 2016)

The theme of the 2016 Public Health Ethics Intensive Course was Healing Family through Social Justice. The goal of the course was "to better understand and honor the concept of family" (Warren, 2015, p. 5). Additionally, Dr. Warren (2016) proposes:

As the perimeters of public health ethics are explored, the framework of population health and well-being become essential to fully understand how to address the violations that impacted the men in the USPHS Syphilis Study. Not only were the men adversely impacted, the notion of family transcended to communities of similar circumstances. Assuring autonomy, benevolence and justice for individuals are the hallmarks of bioethics. However, community engagement, beneficence and social justice must also be employed in order to prevent population-based ethics violations, which were the violations that occurred during the 40 plus years of the USPHSS Study at Tuskegee. (personal communication)

For the 2016 Healing Session, VOFLF/NCBHR sponsored a historical tour to the Centers for Disease Control and Prevention National Archives in Morrow, GA for 27 descendants of the men in the USPHS Syphilis Study. Ms. Head (2016) captured the significance of this part of the families’ journey toward healing by stating:
Personally, seeing for ourselves for the first time the medical records of *Our Fathers,* we were filled with many deep mixed emotions. We sensed their spiritual presence. We felt a sense of empowerment, because, in our hands and before our eyes, we were reading the medical histories of *Our Fathers.* We were eager to read every file and see all those painful and disturbing pictures. We were disappointed and saddened due to the short amount of time that was allotted for viewing/researching the files. We felt flashes of anger upon seeing that little or no health care was provided when the men complained of other serious health issues. We felt deep sorrow and pain for the sufferings and sacrifices our Fathers endured for 40 years, all the while not knowing their fate and trusting in unethical and deceitful medical professionals.

All of us are now inspired to do more, to be the *Voices* for their complete stories. We will never forget what happened to them and why. *Voices for Our Fathers* Legacy Foundation is committed to ensuring that this cruel and dehumanizing study will never happen again. This unprecedented tour has taken an important step in our personal healing and is Voices for Our Fathers Legacy Foundation’s first collective effort in seeking for more facts and truths as descendants. (personal communication)

During the return bus trip from the CDC Archives members reflected on and shared their emotions and feelings on what they witnessed. Ms. Head (2016) added that the visit was “another step forward toward healing. This trip was the most powerful of all. Drs. Ed and Ann Wimberly met us there, which added a degree of support” (personal communication).

The families also visited the Tuskegee Human Civil Rights Multicultural Center and met with Attorney Fred Gray, who successfully litigated against the federal government on behalf of the men and their families.

**Future Plans for VOFLF in 2017**

Two historical activities are being planned for the 2017 Annual Commemoration, which marks the 30th Anniversary of the Presidential Apology. On Monday, April 3, the Annual Family Meeting will be held followed by the First Community Day of Healing Memorial Service at Chisholm Community Center in Little Texas/Macon County, Alabama. Ms. Head (2016) declared that VOFLF “remains dedicated to our mission to uplift and honor the legacy of our Fathers; and to acknowledge the tremendous suffering these 623 African American men endured while they were victims in the United States Public Health Syphilis Study” (p. 1).

Regarding the legacy of the men, Ms. Head (2016) emphasized further that:

All of the Macon County community residents were deeply wounded by the United States Public Health Service Study. It was the longest lasting unethical study in the history of the Public Health Service, 1932-1972. This auspicious event is important because it will provide descendants and the community an opportunity to unite and embrace each other as we remember, honor, and pay tribute to all of these men’s sacrifices. These men’s lives mattered then and their legacy matters now. Everyone is invited to join us in prayer, praise and thanksgiving. (p. 1)

On Friday, April 7, the first $500.00 for the Our Fathers’ Legacy Scholarship will be given to one of the descendants of the Tuskegee Syphilis Family.

**Conclusion**

The VOFLF and NCBRH have used annual commemoration events, family-community building and organizing, and since 2011, family-community healing sessions to engage descendant and community members in addressing the impact of the Study on the lives of the men and their families. Dr. Warren (2014a) expressed:

The fundamental principle of bioethics focuses on autonomy, (individual autonomy), benevolence (intent to do good), and justice (fairness and equality). However, principles of public health ethics demand that, in addition to bioethics we must focus on the group, in this instance, the descendant family members, social beneficence (population good), and social justice (public health). (p. 8)

Thus, community engagement, awareness, and advocacy has been central to the work of VOFLF. Underlying any community engagement process are individuals who share commonalities in terms of either geographic proximity, special interests, or situations that affect their well-being (Glanz, Rimer, & Viswanath, 2015). Three key community engagement concepts that facilitate VOFLF efforts to organize and reach their collective goals are capacity, empowerment/consciousness, and relevance.

Capacity refers to the characteristics of the VOFLF that affect their ability to mobilize as well as to name and to address the key issues concerning the impact of the Study. This includes the development of a sense of community in the Foundation, leadership roles, resources, and active participation by descendant families and community members. Most importantly, capacity building requires VOFLF members to have a strong understanding of the history of the Study and to allow for critical reflection of the Study’s events, its socio-political and cultural contexts, as well as the intergenerational effects of the atrocities that occurred.

Empowerment, in addition to the raising of critical consciousness or awareness, evokes social action and can have an impact at the individual, community, and organizational levels. VOFLF empowers families by transforming historic power relations between key actors involved in the Study such as educational, medical, legal, and government institutions. This empowerment translates into both psychological/emotional empowerment but also creates a sense of civic empowerment and increased social responsibility for foundation members as advocates for public health social justice.

Finally, VOFLF activities and plans of action are relevant and asset-based, meaning the foundation meets people where they are and works with descendant family members and community partners in ways that are mutually supportive; acknowledging the strengths, skills, and resources available within their social networks and family more broadly.
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“Nation to Nation: Family to Family”

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Author Note
The opinions expressed in this article are those of the co-authors alone, and the contents do not necessarily reflect the official policy or position of any other entities. No funding was received for this project and the authors have no financial relationships or conflicts of interest to disclose. The article stems from research, a systematic review, and careful consideration of the following issue: Are we asking the powerful questions that will shift the paradigm of disproportionate health outcomes for African Americans? Let’s break away from the use of traditional definitions and offer expanded ones. The authors acknowledge and thank both the organizers and the highly-engaged attendees/participants at the 2016 Public Health Ethics Intensive themed: Healing the Family Through Social Justice. All correspondence should be directed to Dr. Chukwudi Onwuachi-Saunders.

Abstract
African-Americans in the U.S. suffer disproportionately from chronic diseases, HIV/AIDS and injuries. Powerful questions lead to paradigm shifts, thus what can public health professionals and clinicians ask in order to cause a movement towards optimal health and wellness? What is the right balance of questions and strategies using an expanded versus traditional definitions of identity? For example, what would the health of African Americans present as using the framework of expanded versus traditional definitions of identity? The strategies may include extending client interviews to better identify relationships, documenting supportive community-based relationships, developing treatment plans that include the identified community relationships, and supporting HIPPA waivers to authorize the incorporation of all of the above into health care. Traditional definitions of identity concept are limited. To impact the health and wellness of individuals expanded definitions must be used. Instead of nations, consider communities! Instead of families, consider intimate relationships! These definitions may serve as a more valuable component in relation to assessments and treatment plans. Recognizing individuals’ current community living conditions and social networks plays a critical role in health and wellness. Use of expanded definitions eliminate silos, thus providing a broadened view which will shift the paradigm to optimal health and wellness.

Keywords: Nation, family, health outcomes, health equity, social determinants of health, public health and partners at the table, dialogue, assessments and treatment plans, fostering healing, community engagement/participation, powerful questions to ask - identify relationships, community identity, level of intimacy in relationships, living conditions and social networks, break down silos, a paradigm shift for optimal health and wellness among African-Americans

Introduction
As Public health delves deeper into the discussions on health equity, healthier outcomes, the social determinants of health, community engagement/participation, and other critical discussions, it must continuously ask where is the best place to insert itself in those dialogues to ensure optimum health outcomes and what are the powerful questions to ask. Are all the partners for determining social determinants or health equity at the table? Is public health always the best leader or maybe just a strong partner? What does the right balance really look like in order to cause a paradigm shift towards optimal health and wellness for African-Americans?

Social Determinants of Health
The new paradigm shift proposed in this paper is rooted in the social determinants of health. “Social justice is a matter of life and death. It affects the way people live, their consequent chance of illness, and their risk of premature death (CSDH (2008)).” Additionally, the Commission on Social Determinants of Health emphasizes how these “inequalities in health, avoidable health inequalities, arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by political, social, and economic forces.” “In the United States of America, 886 202 deaths would have been averted between 1991 and 2000 if mortality rates between whites and African Americans were equalized (Woolf et al., 2004).” Social determinants of health include socioeconomic position (social class, gender, ethnicity/racism, education, occupation, income), and structural determinants of health inequities (socioeconomic and political context: governance; macroeconomic policies; social policies - market, labor, housing, land; public policies - education, health, social protection; culture and societal values) (Solar & Irwin, 2010).

Health Education Theory
“The social context in which behavior occurs is always evolving (Glans & Rimmer, 1995).” Therefore, public health and medical practitioners must “understand the importance of cultural backgrounds and the life experiences of community members.” Furthermore, the ecological perspective emphasizes the crucial role of factors within and across all levels of a health problem, including several levels of influence:

1. Intra-personal level - How do I see myself?
   Individual characteristics that influence behaviors such as knowledge, attitudes, beliefs, and personality traits.
In the US, African Americans disproportionately suffer from chronic diseases, HIV/AIDS and injuries. The African Americans experience is not homogenous; but rather it includes peoples from the whole spectrum of the diaspora and several continents. What are the powerful questions that need to be asked to shift the paradigm of health and wellness for African Americans? An example of a powerful question would be: “what would the health of African Americans look like if we identified and used expanded versus traditional definitions of their identity?”

**Proposing A Paradigm Shift:**

**What are the powerful questions that need to be asked?**

A paradigm shift occurs when a question is asked inside the current paradigm that can only be answered from outside of it (Goldberg, 1997). Powerful questions lead to paradigm shifts. For example, Watson and Crick (1968) the scientists asked the question, “what would DNA look like in 3D?” As a result, they discovered the double helix. The question, “where can I get a good cup of coffee in this town,” may have led to the creation of Starbucks Coffee just as, “where can I get a good hamburger on the road” may have led to the creation of McDonald’s (Goldberg, 1997)?

In the US, African Americans disproportionately suffer from chronic diseases, HIV/AIDS, Hepatitis C, and Zika virus; and conditions that commonly occur among seniors, conditions like diabetes and hypertension; emerging and re-emerging infectious diseases such as those with another person or group.

**Traditional Definition of Identity**

Identity is defined as the distinguishing character or personality of an individual, for example, race and ethnicity, sex and gender, or socioeconomic class. These variables or social determinants play a role in determining health outcome.

Traditional definitions of identity include:

1. Nation is a large aggregate of people united by common descent, history, culture, or language, inhabiting a particular country or territory.
2. Community is a social, religious, occupational, or other group sharing common characteristics or interests and perceived or perceiving itself as distinct in some respect from the larger society within which it exists
3. Family is a group of individuals related to one another and living together in a household.
4. Relationship is the state of being connected or related. The mutual dealings, connections, or feelings that exist between two parties, countries, people, etc.
5. Intimacy is a close familiar and usually affectionate or loving personal relationship with another person or group.

**Expanded Definition of Identity**

The level of intimacy defines the significance of relationships. An expanded definition of nations or national identity would include community identity. In addition to asking about family history the questioning should better define intimate relationships, especially in those scenarios where the family structure may be deemed dysfunctional. A community can be created with welcoming attributes. It will present a sharp contrast to how some people live and operate within the confines of the original community into which they were born. Thus, relationships within nuclear or community scenarios may be a more valuable component and criterion, as it relates to conducting assessments and developing appropriate treatment plans. With expanded definitions silos are broken down providing a broadened view towards optimal health and wellness.

How can this be done?

1. Extend client interviews to better identify relationships within the home (for example, caregivers, mentors and role models) and within the community.
2. Document those supportive relationships particularly where there are high risk behaviors, e.g. bullying, abuse, and suicide.
3. Develop treatment plans that include identified community relationships, for example:
   - “Have you asked Mr. A. your band instructor what he thinks about this situation?”
   - “How would Coach Z. tackle and address this issue?”
   - “Ms. B. who drives you to church every Sunday, could she help with your essential errands on the way home from church?”
4. Support HIPPA waivers to authorize the incorporation of expanded definitions in health care.

**Conclusion**

We must acknowledge that “Community” is real and plays a critical role in health and wellness. Additionally, we must recognize the significance to health status of individuals’ current living conditions and social networks. To encourage healing, it is essential to foster the healing power within intimate relationships and not just within genetically defined families. Traditional definitions of family structure are limited. To positively impact the health and wellness of individuals and patients, the onus is on public health professionals, health care providers, community health educators, sociologists, clergy, health insurers, and others to begin using more expanded definitions of identity. Instead of nations, consider communities! Instead of families, consider intimate relationships!

This new paradigm should provide additional insight for the improved management of various health and social conditions that manifest in different sub-groups of our communities, including but not limited to the management of substance abuse; chronic conditions like diabetes and hypertension; emerging and re-emerging infectious diseases such as HIV/AIDS, Hepatitis C, and Zika virus; and conditions that commonly occur among seniors.
e.g. dementia. Public health and other professionals can apply this new paradigm and expanded definitions during interactions with clients. Efforts of practitioners who implement these new expanded definitions and paradigm will help to authenticate them and further demonstrate their expected benefits.

Breaking away from the use of traditional definitions, and using expanded definitions will reflect the reality of lived experiences in community. Deployment of these expanded definitions of identity will allow for asking the powerful questions that will shift the paradigm of disproportionate health outcomes for African Americans towards optimal health and wellness.

References


The School as an Extension of the Family

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Abstract
Dr. Jacqueline Brooks’ 2016 presentation examined the role that families must have in the educational lives of their children. She examined the obstacles that children of color continue to experience in this country’s schools and educational systems. In this article, Clyde C. Robertson explores the history of African American education. He scrutinizes the challenges African American families have had, while attempting to educate their children. Furthermore, he delves into the theories and philosophies of African Centered educators who argue that African American educational professionals should develop curricular that liberate African American students, families, and communities. Their premise is that liberated people construct and sustain healthy communities that are globally connected, secure, and sustainable.

Keywords: African Americans, African Centered education, African Centered curriculum, emancipatory pedagogy, educational narrative, post bellum south
Introduction

In 1919 the Harlem Renaissance writer, Claude McKay, responded to the Red Summer, during which no less than 28 African Americans were lynched, by penning the following protest limerick:

If we must die, let it not be like hogs...hunted and penned in an ignoble spot...While round us bark the mad and hungry dogs...Making their mock at our accused lot...If we must die, O let us nobly die...So that our precious blood may not be shed in vain, then even the monsters we defy shall be constrained to honor us, though dead! Oh kinsmen, we MUST meet the common foe! Though far outnumbered let us show us brave! And for their thousand blows, deal one death blow! What though before we lay, the open grave? Like men we’ll face the murderous, cowardly pack, pressed to the wall, dying, but fighting back (pp. 20-21).

This poem typifies the combative spirit with which African Americans faced the vicious onslaught of racism and intolerance. At the turn of last century, and only a few decades removed from deleterious bondage and enslavement, African Americans pursued value systems inherited from their great ancestors. They created towns, commercial districts, and institutions which all served as buffers from the scorn of white supremacy.

Tuskegee University is an example of an institution created by 19th century African Americans as a form of opposition to second class citizenship. Along with churches, schools provided African Americans with a tangible sense of belonging and security by providing both cognitive instructions and valuable lessons of resistance. Simply learning how to read, write, and compute were concrete signs of opposition to those who had, at sword and gun point, prohibited these courageous people from pursuing an education. James Anderson (1988), the author of The Education of Blacks in the South, 1860-1935, stated that, “African Americans emerged from slavery with a strong belief in the desirability of learning to read and write” (p. 6). This Fact was further substantiated by the following quote uttered by a formerly enslaved person, “There is one sin that slavery committed against me which I will not forgive; it robbed me of my education” (Anderson, 1988; p. 8). Soon after emancipation, entire families attended makeshift schools and, together, struggled to learn.

And so, as I grapple with the topic of The School as an Extension of Family, I will do the following:

1. Examine African American education history,
2. Probe the concept of African Centered education, and
3. Explore the importance of including the family and community in the education of African American youth.

African American Education History

At the end of the Civil War, African Americans were freedmen/women in a land in which they had once been enslaved. Very few of them had any recognizable form of education. The vast majority of freedmen/women could not read, write, or compute. Newly freed African Americans longed for an education that would allow them to compete and be accepted in a country where they had formerly been scorned, abused, and abandoned. After their emancipation in 1865, many African Americans rushed into the nearest dilapidated, makeshift schoolhouse that offered even the slightest academic lessons. During her explorations of the post-war South, Harriet Beecher Stowe, the author of Uncle Tom’s Cabin, observed this phenomenon and wrote the following, “They rushed not to the grog-shop but to the schoolroom—they cried for the spelling-book as bread, and pleaded for teachers as a necessity of life” (Anderson, 1988; p. 5).

Robert Russa Moton, Tuskegee University’s second President, grew up in war ravaged Virginia. His devotion to education began shortly after his birth (1867) in Amelia County, Virginia. His oldest memory was of his mother, Emily Brown, working in the field all day and conducting night school in the evening. “Among my earliest recollections,” recalled Moton, “is the fact that my mother frequently, after working in the field all day, would hurry us through the evening ordeal in order to get the cabin ready for the night school which met regularly in our meager cabin” (Hughes & Patterson, 1956; P. 6).

Moton’s mother understood the importance of educating people who had been denied access to the most rudimentary schooling. She viewed education as an essential element to living a free and fulfilling life. This overwhelming commitment to teaching and learning inspired Moton to pursue education as a form of resistance to tyranny, exploitation, and terrorism. The educational self-determination displayed by Emily Brown, Moton’s mother, was a common practice among African Americans.

A major misconception about this period is that the newly emancipated people were totally dependent upon “Yankee” missionaries for their education. Anderson (1988) addressed this point when he said, “The values of self-help and self-determination underlay the ex-slaves’ educational movement.” He continued, “To be sure they accepted help from the northern missionary societies, the Freedmen’s Bureau, and some southern whites, but their own action - class self-activity informed by an ethic of mutuality - was the primary force that brought schools to the children of free men and women” (p. 5). To extenuate this point, Anderson provided the following quote from William Channing Gannette, a white missionary teacher from New England, “...they have a natural praiseworthy pride in keeping their educational institutions in their own hands...what they desire is assistance without control” (1988; p. 5).

As previously demonstrated, African Americans understood that education was vital to establishing a self-determined and sovereign community. Because of which, both southern and northern whites began to impose greater control and influence over African American education. According to Anderson (1988), “It is crucial for an understanding of American education history to recognize that within American democracy there have been classes of oppressed people, and that there have been essential relationships between popular education and the politics of oppression” (p. 7).

It was during these post-Civil War years that both northern and southern whites became agenda setters and gate keepers of African American education. Of course, many whites opposed African Americans from obtaining any form of education. However, not all whites were opposed to freedmen/women receiving schooling. Some moderate southern and northern whites encouraged a limited and controlled education for African Americans, “...they believed that universal schooling,” according to Anderson, “would socialize the young to the discipline and values needed for efficient service within social roles prescribed along race and class lines” (Anderson, 1988; p. 279-280).
Educational Centeredness

The aforementioned query is addressed by the concept of African Centered education. Curriculum/content is at the core of African Centered learning. The historian, Carter G. Woodson, addressed the necessity of establishing salient academic content for African Americans in his seminal book, *The Miseducation of the Negro* (1933). In this text, he insisted that the curricular offered to African Americans should be inclusive and liberating. He strongly suggested that the education most "Negroes" received was inadequate and inferior. According to Woodson, "...the educational system as it has been developed in Europe and America...does not hit the mark even for the white man himself." He furthered his diatribe by saying, "If the white man wants to hold on to it, let him do so; but the Negro, as far as he is able, should develop and carryout a program of his own" (1933: p. xi).

Woodson realized that African Americans had been conditioned to accept inattention and second class citizenship. He also understood that the average African American's education validated and accentuated his/her woeful status throughout the land. Woodson (1933) confirmed his view by positing, "Negros daily educated in the tenets of such a religion of the strong have accepted the status of the weak" (p. xii). Woodson continued to connect the plight of African Americans to an abysmal educational system when he suggested, "No systematic effort towards change has been possible, for taught the same economics, history, philosophy, literature, and religion, which have established the present code of morals, the Negro's mind has been brought under the control of the oppressor" (1933: p. xii).

In 1933 Woodson, the consummate scholar and historian, stressed the importance of expanding the curricular offered to African Americans. He recognized, in people of African descent, the harmful psychological impact of having been convinced that neither they nor their ancestors had contributed anything to world progress. "The same educational process which inspires and stimulates the oppressor with the thought that he is everything worthwhile, Woodson said, "depresses and crushes at the same time the spark of genius in the Negro by making him feel that his race does not...measure up to the standards of other people" (1933: p. xiii).

In addition to having identified the negative effects of academic racism on African Americans, Woodson also offered solutions. He suggested that school content include and examine Africans and African Americans. To this end he wrote, "After Negro students mastered the fundamentals of English...and the leading facts in the development of its literature, they should not spend all of their time in advanced work on Shakespeare, Chancer and Anglo Saxon," Woodson asserted, "They should direct their attention also to the folklore of the African, to the philosophy in his proverbs, to the development of the Negro in the use of language, and to the works of Negro writers" (Woodson, 1933: p. 145). Woodson, unapologetically, placed the
Family and Community in the Education of African American Youth

Emancipatory pedagogy also encourages schools (administrators, teachers, & staff) to establish healthy relationships with the students’ parents and community. Adelaide Sanford (2006), in the book Teaching Children of Color: Seven Constructs of Effective Teaching in Urban Schools stated that, “Respect and validation of family and community are essential to the rich meaningful instructional program—one that is productive for children in terms of the fulfillment of life’s meaning, not just the passing of examinations” (p. 19). Administrators who ostracize parents and the community from their school, risk creating a major disconnection with many of their students.

Teachers and administrators must also develop a healthy connection with and understanding of the communities in which African American students live. “In the community where I lived and taught for 35 years, many teachers did not know anything about the people of African ancestry.” Said Sanford, “So it was absolutely essential to go beyond telling teachers that they had to respect parents and the community; you had to give them experiences that would form the bases for the development of that respect” (2006; p. 20).

In many traditional settings, teachers attempted to alter the cultural trajectory of African American students. Educators historically have struggled to make “good Americans” out of students who invariably practiced their community’s long established cultural norms. Teachers routinely attempted/attempt to correct the neighborhood English that is often spoken by the schoolchildren. Of course, students must learn how, when, and where to use proper English. However, the neighborhood English spoken by the students must not be criticized, a mistake often made by educators.

Sanford addressed this issue when she postulated, “Unfortunately, too many of the people teaching our children have absolutely no idea that their students’ families have cultural traditions, high ethical codes, and established standards of behavior” She further noted that, “they are unaware of the community’s rich history and culture that have been kept as essential elements of survival” (2006; p. 21). Teachers must immerse themselves into the total life of the student, which means developing wholesome relationships with families and communities. Joyce King and Clyde C. Robertson (2007), supported this contention in the article titled, “Bon Feerey: A Teaching and Learning Methodology for Healing the Wounds of Distance, Displacement, and Loss Caused by Hurricane Katrina.” The previously mentioned scholars wrote, “Teachers must be active participants not just in the use and dissemination of this kind of curriculum content knowledge but also in its development.” King and Robertson also declared, “Furthermore, creating a cultural community perspective is essential for good teachers and good teaching” (p.475). Sanford stated it perfectly when she said, “So you take what families are, need, know, and are interested in to build a curriculum that enhances your whole school program” (2006; p. 24).

Conclusion

For African Americans, and other marginalized people, education must be used as a form of resistance and liberation. Historically, schooling has been used to force African Americans into becoming “ideal Americans”. African Americans were/are encouraged to subscribe to the notion that the only substantive narrative has been written by people of European descent. This practice has led many people of African descent to look askance at education and educators; a practice which has weakened their families and communities. Contrastingly, African Americans must recapture the educational narrative in a way that properly informs, emboldens, and prepares them to compete as equals in a global setting. This approach must include, in a very meaningful way, the families and communities from which these students come.

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The Necessary Roles of Family and the Purpose of Education

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Author Note
The opinions expressed in this article are solely those of the author and do not necessarily reflect those of the institution where he is employed.

Abstract
This article was written in response to Dr. Jacqueline Brooks's keynote speech entitled, “The School as an Extension of Family,” presented at the National Bioethics Center for Research and Health Care 2016 Public Health Ethics Intensive and the Annual Commemoration of the 1997 Presidential National Apology at Tuskegee University. This article is intended to pay homage to the lives of 623 African American men who were grievously wronged in the United States Public Health Service Syphilis Study (USPHS) at Tuskegee.

Keywords: Family, United States Public Health Syphilis Study at Tuskegee, U.S. Presidential National Apology, African American men, Education

Introduction
As the daughter of one of men in the USPHS Syphilis Study, men, Freddie Lee Tyson, and President of the Voices for Our Fathers Legacy Foundation (non-profit for the descendants of the USPHS Syphilis Study) my response centers on “The Necessary Roles of Family and the Purpose of Education”. Attempts will also be made to discuss responsibilities and ethical behaviors of those persons who have college, graduate and terminal academic degrees.

The Most Powerful Words in This Topic are Family and Education
To illustrate the power and influence a mother has on her child’s interest in learning and personal achievements an amazing story can be used here as an example.

There was a little boy born enslaved to a single mother. He lived with his mother, older brother and younger sister in a one-room, run-down 8x10 cabin. Every night he along with his brother and sister slept on a pile of dirty rags on the dirt floor. This little boy never knew the identity of his father. As a small child, he was burden with daily chores on the plantation beginning before sunrise and lasting after sunset. Hunger pains were his constant companions. He, along with his family suffered the worst of dehumanizing conditions and treatments for the first 9 years of his life. Still, he longed to learn and to know what it would be like to go inside the schoolhouse as his young “missus”. Once he said that, “he felt that going inside this schoolhouse must be much like getting into heaven”. His pining to learn never went unnoticed by his mother. As the cook on the plantation, she had to cook in an open hearth three meals a day for 26 people, 16 free and 10 enslaves. His mother could not satisfy the physical nor mental hunger her children suffered. Her resilience, work ethics and loving demeanor set an example for her young children to be and do their very best. Her prayers for freedom and the opportunity for a better life were answered on April 5, 1865.

Understanding the value of knowing how to read, spell, write and count numbers, she obtained a little blue back spelling book and found a school for him soon after leaving the plantation. Still burden with the hardship of long working hours in the salt mines, he carved out time for studying his little blue book and going to school with much encouragement from his mother.

As the next few years passed during his childhood years, he received support from, his teacher and the woman he worked for while living in this small impoverished community. This young boy’s dreams of being inside a schoolhouse and learning had become real (Washington 1995).

This young boy was Booker T. Washington, one of the founders, in fact the founding Principal, the first Principal of the historic, Tuskegee Institute, today known as the historic Tuskegee University. It was within his family that he first was inspired and developed the will and felt the passion to learn. At the age of 25, he understood that education had made it possible for him to better himself but he was also responsible for helping others to better themselves through education too.

The institution of slavery no longer exists in our nation. Yet, there are too many poor performing schools and families living in improvised conditions that contribute to enslaving intellectual growth and hinders achievement. In addition to these circumstances, there are social injustices and challenges that confronts children and their families every day. If families are deeply affected by this environment, then the education system will surely be impacted.
Articles

There are times when interruptions and misfortunes seem to constantly disrupt the teaching and learning process in schools today. The need for a loving, nurturing family and community must become the space where the seeds are planted and cultivated for growing the individual’s wills and aspirations of becoming the best of oneself and for others.

However, emphasis should not always focus on the paralyzing challenges and obstacles that often compromise family life. Instead, more attention should be given to embedding the proven merits and characteristics that are necessary components for building strong and caring families. As well as, how both, families and education, are connected and critical to essentially creating a more humane society and a better world. According to HealthFamily.org:

Families should be built on relationships of love and affection, service and gratitude, giving and receiving, mutual respect and understanding, teaching and learning, helping and sharing, trusting and confiding, believing and hoping. It is in the home that a child first learns the meanings of moral support, re-assurance in times of doubt, comforting in times of sorrow, encouragement in the face of uncertainty, and consolation in the face of calamity. Character and self-discipline begin developing in the family. Self-worth and the worth of others, moral values and ethics begin shaping in the family. A child’s faith journey and their spiritual life all begin within the walls of their homes. The home is the place where children first become curious about the world around them. They show their interests in learning, by touching, listening to bedtime stories, pulling things down and exploring forbidden places. It is these early experiences in a child’s life when the family’s values must be present to properly provide an environment, which therefore will enhance mental and physical developmental stages (HealthyChildren.org).

These qualities and experiences of a strong family are possible to maintain, even during the most difficult times when they appear overwhelming and insurmountable. The school as an extension of the family is at times the best environment where a child can learn. Education is one of the most powerful resources available and essential for creating, strengthening and maintaining strong families. Strong families build strong individuals, strong individuals develop strong communities, strong communities make strong nations, and strong nations create a better world.

The family is the Soul of Society, and Education is the Heart

Education dates back over 3500 years ago in Greece. It has been an integral part of civilization for thousands of years. Education is progressive, it has enabled human beings, generations after generations to become more aware and knowledgeable of the world in which they live and a better understanding of the people they share this world with. The primary purpose of education should be to make individuals better human beings. Education provides the freedom to make informed and ethical choices, to acquire extensive knowledge, to become independent thinkers, and capable of making rational and moral decisions. Ultimately, an educated person should treat and regard all men and women with dignity and respect. Education will prepare individuals to become good citizens and leaders in their communities; allow them to have employment opportunities, and secure financial stability.

Conclusion

The word education comes from the Latin word e-ducere, meaning “To lead out.” Knowing the origin of the word education, Booker T Washington once again demonstrates an excellent example of the purpose of education and responsibility of an educated person with unquestionable ethical and moral values. After slavery, newly freed African Americans were uneducated poor people in the south’s rural communities. They were in desperate need of a formal educational system. A mere 16 years after slavery ended in 1867, a young former enslaved boy received formal educated and was willing to use his education “to lead” other former slaves, all Black people during that perilous time when the United States was still adjusting to the aftermath of the Civil War, into their new world. In 1881, Tuskegee Institute, now University was founded upon these principles of education; honorable character, impeccable work ethics, trust, serving others and becoming better men and women. Booker T. Washington’s teachings were not limited to the school’s grounds, but the hundreds of residents, longing to learn, living in rural Macon County, Alabama. He realized that for his race (Black people in the United States) to experience true freedom, they must begin with education. He believed that it was not enough for someone to become educated for their personal gains, nor for Tuskegee Institute to educate only the students on campus. But, the school must reach out to all families in Macon County. With help from the Rosenwald Foundation and others he developed model educational curriculums for the one or two room schoolhouses for rural communities in Macon County and throughout the South. These small schools were indeed an extension of the families and the communities. The schools are known, as the Rosenwald Schools. They were the only schools available for educating Black children, former slaves and descendants of slaves, throughout the segregated South for more than 75 years.

As I engage in the so-called “bull sessions” around and about the school, I too often find that most college men have a misconception of the purpose of education. Most of the “brethren” think that education should equip them with the proper instruments of exploitation so that they can forever trample over the masses. Still others think that education should furnish them with noble ends rather than means to an end. It seems to me that education has a two-fold function to perform in the life of man and in society, one is utility and the other is culture. Education must enable a man to become more efficient, to achieve...legitimate goals in life.

Dr. King went on to state the function of education, therefore, is to teach one to think intensively and critically. But education, which stops with efficiency, may prove the greatest menace to society.

We must remember that intelligence is not enough...Intelligence plus character—that is the true goal of education.
Prelude to a Revolution: Expanding the Power of the Black Lives Matters Movement to Decrease Deaths Caused by Legal Intervention in the United States

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Abstract
The Black Lives Matter Movement (hereafter BLM) is crystallizing at a critical time in American history. Although its focus has been specifically on the treatment of African Americans by the repressive ideological and political structures of the United States, the group of young Black students, activists, and their allies have started a discussion that reverberates around the issues of race, ethnicity, and nationalism fermenting across the vastly changing landscapes of American subcultures and geo-political spaces. More specifically, the BLM Movement has provided a powerful context in which a broader movement can serve to educate, highlight, and improve the lives and living standards of ethnic minorities having a positive impact on the health disparities from which they suffer. This descriptive analysis examines the origins and awakenings that the BLM Movement has arisen and the social and political awakening that it could promote. Its

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King, Martin Luther, Morehouse College Student Paper, The Maroon Tiger, in 1947.

Introduction/Background

No other minority group has been as pivotal in the expansion of freedom and citizenship in Western civilization as people of African descent. The voices and actions of Olaudah Equiano, Frederick Douglas, Sojourner Truth, Harriet Tubman, Nelson Mandela, and Martin Luther King Jr. highlight the social, moral, and political power that the Black presence has displayed throughout societies of the West and colonial spaces. And now the BLM Movement, developing socially and politically in 2015 in the United States, has also the opportunity to continue the expansion of freedom and citizenship at the dawn of the twenty-first century. The Movement’s message is clear. If every life matters then what is the role of the nation-state to its people and what role does its people have in defining and controlling the excesses of the State?

The organization of the BLM Movement has spurred a remarkable conversation regarding the role that the State plays in creating a just livelihood and citizenship for Black Americans. By highlighting the injustices and unequal standards applied by State apparatuses local and state arms of government, the Movement has forced political leaders to address the growing disparities between the poor and the wealthy and ultimately the disparities existing between ethnic minorities and White America. With this new awakening around the lives of Black Americans, the Movement has an opportunity to continue the conversation on biopolitical power and the role it has in protecting the livelihood of all of its citizens.

By describing the national sources of intentional injuries by Law Enforcement in the U.S. this study examines the genesis and possibilities of the BLM Movement and the opportunity it has in crafting a more ethical description of the health disparities created by the State apparatus in its attempt to promote the general welfare of the people. Focusing on the confluence of events, technologies, and policy shifts that have intersected with the BLM Movement’s critique of current practices and its argument for the value of black life in the United States, it is demonstrated that the BLM Movement has the makings of a major critical socio-political voice. First, drawing in part on the scholarship of Michelle Alexander and Ta-Nehisi Coates, the role that racism, nationalism, and biopolitical power play in the lives of people of color is examined. Secondly, through a review of the types and representative power of data collected in national databases prior to and since the Movement, the opportunity that the BLM Movement has in revitalizing the role of Black Citizenship is crystallized. Lastly, I contemplate the possibility the Movement has to revitalize the voice and moral force of Black humanity in local and national affairs.

Black Lives Matter: A Genesis of Technology and Social Politics

The BLM Movement is the manifestation of many social, economic, and political intersections. In the digital age of social media, the arrival and development of the organization highlights the instantaneous effect of news reaching interested parties in real time. The Movement’s emergence also illuminates the proliferation of news cable channels following the interest of many social and economic constituencies to feed a 24-hour news cycle. The BLM Movement website asserts that its organization was founded after the murder of Trayvon Martin, a young teenager walking home from a convenient store with a soda and skittles. Building on the intra-racial discussion of the value of Black Life and the role the state of Florida played in creating an atmosphere where civilian could murder a black child and claim self-defense, the BLM Movement ignited a new generation of young college students, social activists, and artists committed to addressing the injustices and inequalities suffered by Black Americans.

The youth surrounding the creation of BLM are unlike Black social movements of the past. The Movement’s introduction as an organized entity and social group has its origins in new social media that enables people to congregate in the virtual world by the new hashtag culture. The BLM Movement used the trauma of Trayvon Martin’s murder as the pivotal event to awaken the Black community to the racism of its not so distant past. As a result, the Movement has created a community among a new generation of young people whose interest and concerns are varied and concentrated their collective focus on issues of race, race relations, and institutional racism that limits their opportunities and freedom of movement in the United States.

Moreover, the BLM Movement has capitalized on the power of digital technology to mobilize interested people regardless of class, education, or geographical space. Its website speaks to the groups intentions to frame Black issues in a larger social and historical context. It is not only concerned with the death of Trayvon Martin, but with the power of the State to define the value of the teenager’s death by criminalizing his past. The organizers posted:

#BlackLivesMatter was created in 2012 after Trayvon Martin’s murderer, George Zimmerman, was acquitted for his crime, and dead 17-year old Trayvon was post-humously placed on trial for his own murder. Rooted in the experiences of Black people in this country who actively resist our de-humanization, #BlackLivesMatter is a call to action and a response to the virulent anti-Black racism that permeates our society (http://blacklivesmatter.com/).

Once again, the death of Trayvon Martin serves as vehicle to articulate a particular trauma and realization within the Black community. The BLM Movement’s emphasis on the Black body marks a particular racial history that marks the racial presence of the country’s nationalism against the presence of Black bodies that the protest movement must organize against. Thus, as the Trayvon Martin trial revealed, Black humanity, or the worth of the young teenager’s life, was argued against the amoral and yet deemed legal behavior of his accuser. Amplified by the rash of sudden deaths of Black Americans under the control of policemen, the BLM Movement has helped bring the issue of humanity to the forefront and has refocused the country’s attention upon the forces that inhabit everyday life.
More importantly, the BLM’s Movement tapped into a Black American sentiment that justice was punitive for Black Americans and restitutive towards White America. On the one hand, when Black men are implicated in violence, they are swiftly pushed through the judicial system without adequate protections or legal representation by prosecutors who often push for maximum sentences. On the other hand, Black Americans watch as white violent behavior especially against Black Americans are slowly moved through the judicial system and seldom prosecuted by District Attorneys. Hence, BLM’s Movement has compelled the nation to negotiate and discuss trauma of Black people whose is quickly moved into the mass incarceration state apparatuses as criminals and slowly advocated for if their lives are lost. The Movement has also forced White America to respond to the lack of accountability, sympathy, and coverage of Black loss of life. President Obama’s statement, after the decision not to prosecute the white policemen in the killing of another teenager Mike Brown in Ferguson, Missouri, reflects the frustrations of Black Americans. The President stated, “In too many parts of this country a deep distrust exists between law enforcement and communities of color”, he said. “We need to recognize that this is not just an issue for Ferguson. This is an issue for America.” In signifying a larger emotional trauma revisited upon Black Americans after each arrest of their citizens by the state apparatus and the lack thereof against white accusers, the President articulates a visceral feeling within the Black community that white lives are more valued and that the officers of the State are set against them. The BLM Movement has captured this sentiment in its slogan and protest and has succeeded in forcing the American public to negotiate the value of Black American life.

President Obama Policy Changes and the National Violent Death Reporting System (NVDRS)

Using his platform to not only give voice to the sentiments of Black America, President Obama also directed resources and policy changes that significantly improved the ability to collect and describe the impact of intentional injury by legal intervention. As the President of the United States, Mr. Obama, has limited ability to regulate for the general welfare of the populace. By constitutionally mandated sovereignty the States have exclusive powers to police and protect its citizenry. Prior to the Movement, the Centers for Disease Control and Prevention (CDC) collected data through its National Violent Death Reporting System (NVDRS) from only six (6) states and reported said data through its WONDER Internet search tool and upon individual request of researchers that purported to represent the incidence and prevalence of violent deaths for the entire country. States that are funded for NVDRS operate under a cooperative agreement with CDC to whom all violent deaths are voluntarily reported. In 2016 CDC received funding to expand the system to a total of 42 states. The goal is to include eventually all 50 states, all U.S. territories, and the District of Columbia in the system.

The CDC currently reports through the WONDER Internet based search system intentional deaths from 1981-1998 and 1999-2014. One significant point in the break in the data reported between 1998 and 1999 is legal intervention was made a separate category to be reported beginning in 1999 and a more significantly started being reported among the top ten leading causes of violent deaths for Non-Hispanic African American men ages 15-19, 20-24, 25-34, and 35-44. Ironically as indicated in Figure 1, even with the significant increase in the number of state contributing data to the NVDRS after the addition of the new states Trayvon Martin is still uncounted among the deaths reported because Florida is not a participating state.

The BLM’s Movement reflects the evolution of Black scholarship, which has been decades into the making. Over twenty years ago, William Julius Wilson and his influential book *The Truly Disadvantaged: The Underclass and Public Policy* (1990) initiated a movement of study on how race, poverty, and public policy affected the lives of African Americans. Similar to W.E.B. Du Bois study of Black Philadelphians in *The Philadelphia Negro* (1899) and their strained relationship to the local and state governments in Pennsylvania, Wilson’s study of black employment, culture, and relationship with local governments highlighted a growing schism between Black Americans and the local and state governments responsible for providing equal and full citizenship to its citizens. African Americans have always had an ambivalence towards the African nation-state since most rights African Americans have enjoyed have been issued directed through Federal laws but never applied equally by the states. Wilson’s scholarship marked a renewed discussion of Black lives and the role of the state in providing equal

![Figure 1: States Currently Reporting to National Violent Death Reporting System (NVDRS)](Image)
This awareness has manifested further in the work of Michelle Alexander and Ta-Nehisi Coates. Arguing the predatory and discriminatory nature of police profiling and mass incarceration policies and how they effectively lesson the ability of a large portion of the Black population from competing with White America for employment, housing, and political power, Alexander’s The New Jim Crow: Mass Incarceration in the Age of Colorblindness (2010) has seen a slow and eventual rise as required reading in Black Studies, Criminal Justice, and Sociology Departments laying the foundations for the Black Lives Matter movement to make its consequential argument that the State is valuing the life of White Americans at the cost of Black people. Alexander reveals how the “War against Drugs” exploited the vulnerability of poor Black communities for political gain while disengaging and disenfranchising Black political participation. The scholar writes, “Once you’re labeled a felon, the old forms of discrimination—employment discrimination, housing discrimination, denial of the right to vote, denial of educational opportunity, denial of food stamps and other public benefits, and exclusion from jury service—are suddenly legal (Alexander, 2)." For Alexander, the criminal justice system works as an agent in reinforcing the legacy of slavery and Jim Crow in its policing of Black communities. The scholar’s argument fortifies the Movement’s argument that Black life is under attack in the State apparatuses of America.

For example, Alexander’s influence on the BLM Movement is found in its opening statement of the group’s website’s creation and mission. The group lists Black and Latino incarcerations as one of their pivotal concerns. Moreover, they also point to the statistics that reveals the disparity of incarceration rates between Blacks and White Americans when compared to the percentage of the population as a whole. The organizers note:

- Blacks and Latinos are about 31 percent of the US population, but 60 percent of the prison population.
- In our country 1 in 3 black men will be incarcerated in his lifetime, and Black women are the fastest growing prison population. (http://blacklivesmatter.com/).

These statistics show the Movement’s critique of the American Nation-state. Calling attention to the overrepresentation of Black and Latino Americans in American prisons, the Movement’s concern is not only with the alarming rate of Black incarceration, but also reveals that this is also a problem facing other minorities in the United States. Either people of color are committing enormous amount of crimes or communities are being targeted. Although White conservatives and their allies have tried to vilify the Black community and blame immigrants within their midst, scholarship, such as Alexander among others, has revealed a predatory effect upon communities of color. Moreover a critical analysis of the source of information provided to the general public regarding the incidence and prevalence of legal intervention death and injury indicates that the numbers have been grossly under reported.

References


**Abstract**

Using an assemblage methodology that relies on theology, philosophy, social science and the musical genre known as the Black spirituals as critical resources, Rev. Cook’s response posits religion as an ethically ambiguous social construct rife with nascent socio-political potential that is shaped for the good or ill of a society by the imagination and consequent praxis of a religious community. He holds the “good religion” sung about in the slave songs as a religious ideal and commitment bursting with political consequences and social possibilities. Though always limited in its scope and purity, “good religion” can be actualized in religious adherents’ ability to do religion in a way that protects human life, and perpetually strives to arrange society for the benefit of the entire human family; especially the marginalized.

**Introduction**

In her presentation, Dr. Moni McIntyre asserted that religion is inextricably bound to questions of identity. She says, “When we ask, ‘who am I?’ from a Christian perspective, we find ourselves as one of a group, one of a family, one of an ethnic group, one of a group known as humanity.” We identify ourselves as part of specific stories. A component of those stories are the socio-cultural particularities that shape our individual experiences and narratives. One element of those socio-cultural factors is religion.

Theologist Paul Tillich defines religion as encompassing that which concerns humanity ultimately. He says, “The ‘situation’ theology must consider is the creative interpretation of existence, an interpretation which is carried on in every period of history under all kinds of psychological and sociological conditions” (Tillich, 1973, p.4). Tillich defines...
Articles

“ultimate concern” as that which concerns us unconditionally; at all times and in all places... “that which determines our being or not-being...Man is ultimately concerned about his being and meaning” (Tillich, P., 1973, 14). One way to conceptualize “ultimate concern” would be to answer the question what keeps me up at night? And/or what makes me get up in the morning? This is what religion is primarily concerned with. In fact, Martin Luther King, Jr. once said of religion unable to address the realities of the human condition, “Any religion that professes to be concerned with the souls of men and is not concerned with the slums that damn them, the economic conditions that strangle them, and the social conditions that cripple them, is a spiritually moribund religion” (King, M.L., 1959).

Religion is central for creating healthy communities of discourse and practice because it encompasses both particular and universal claims about human identity (-ties). In the Abrahamic faiths, the question of human identity is answered by positing human being as created by God, participating in the ultimate being of God, and, therefore, endowed with incredible potential. However, who we are is not just a personal, private matter as is often the case in the “rugged individualism” of the neoliberal American economic structure, where who I am matters for me and me alone. As Dr. McIntyre stated, “Doing Christian religion honestly requires us to do religion socially.” Who human beings are as creations of God, endowed with burgeoning potential is rife with socio-political implications.

“Have you got good religion?”

Being human is not only about the possession of potential, but it is also about being able to actualize the potential one possesses. This is the essence of human freedom. Theologian Howard Thurman said, “The degree to which the potential in any expression of life is actualized marks the extent to which such an expression of life experiences wholeness, integration, and community” (as cited in Fluker & Tumber, 1999). Consequently, the most significant socio-political question for religion is always is society arranged in a way that promotes the actualization of human potential? Does what or who religion says humanity is (valuable, potential-full beings) match bow humanity is made to live (social reality)? When a discontinuity is apparent, good religion - the kind my slave ancestors asked about in the spiritual “Have You Got Good Religion” - must rise up with prophetic conviction and creativity, empowering people of faith to both challenge and develop sustainable solutions to injustice.

Certainly, religion does not do this perfectly. Religion is always interpreted through the mouths and hands and feet of flawed humanity. As such, religion has often been one of the most devastating forces abused by the dominant to justify their malfeasance. Nevertheless, religion can never be completely discarded as entirely useless and harmful; for while it is used as created by God, participating in the ultimate being of God, and, therefore, endowed with incredible potential. However, who we are is not just a personal, private matter as is often the case in the “rugged individualism” of the neoliberal American economic structure, where who I am matters for me and me alone. As Dr. McIntyre stated, “Doing Christian religion honestly requires us to do religion socially.” Who human beings are as creations of God, endowed with burgeoning potential is rife with socio-political implications.

Poverty robs marginalized humanity of their God-given ability to actualize their potential. Elizabeth Amoa’s words in her essay “African Traditional Religion and Poverty” are insightful. She says, “Poverty...degrades and dehumanizes people...common humanity demands that those in poor communities must be helped to regain their dignity in order to become human beings again.” (Amoa, 2009, p. 115). It may be impossible for the rich to gain entrance into the kingdom of heaven, as Jesus once taught; but it is just as unattainable for the poor to gain access to the promises of American society without the doors being opened.

In his recent work, Democracy in Black: How Race Still Enslaves the American Soul, Eddie Glaude tells the story of a 65-year old black woman named Christine Frazier, who lost her home after losing her job in the economic crisis of 2009. She had paid $240,000 on a home that had been reduced to $40,000 in value. Christine recalled in vivid detail the day she was evicted by police.

Without a doubt, there is a wide chasm between the religio-political dignity we say should be afforded humanity and the indignity in which most of humanity lives. People of faith must face the fact that we live in a world in which the eighty-five richest people in the world own as much wealth as the entire bottom half of the world's population (about 3.5 billion people) (Shin, L., 2014).

This picture of social neglect and misery is even more vivid when considering national statistics:

1. In 2014, African-Americans were more than twice as likely to be unemployed (11%) as their white, non-Hispanic counterparts (5%) (Bureau of Labor Statistics, 2014).
2. One in four (26%) African American households are food insecure as compared with one in 10 (11%) of Caucasian households and one in seven (14%) households overall (Coleman-Jensen, Rabbitt, Gregory & Singh, 2015).
3. More than one in three African American children (34%) live in food-insecure households as compared to one in seven (15%) Caucasian children (Coleman-Jensen, Rabbitt, Gregory & Singh, 2015).

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In Chicago, where I was born and reared and where much of my academic research has been focused, there have been over 5,000 murders since 2001, and gang membership is estimated at over 100,000 (Loury, 2013). Despite the constant dumbfounded responses of this nation’s leaders to Chicago's glaring statistics, the city's condition should be no surprise when 92% of Black male teens, ages 16-19 (the racial, gender, and age demographically most likely to become gang members) are unemployed. The highest unemployment rate in the nation (Dyer, 2014). Similarly, the city of Boston, where I now live and serve as a pastor, has the largest racial wealth gap in the country. A recent report published by the Federal Reserve Bank of Boston titled, “The Color of Wealth,” based on data collected using the National Asset Scorecard for Communities of Color (NASCC) showed that the average white Boston family has $246,500 in wealth, while the average Black Boston family has a mere $8 (The Color of Wealth, 2016).

In his recent work, Democracy in Black: How Race Still Enslaves the American Soul, Eddie Glaude tells the story of a 65-year old black woman named Christine Frazier, who lost her home after losing her job in the economic crisis of 2009. She had paid $240,000 on a home that had been reduced to $40,000 in value. Christine recalled in vivid detail the day she was evicted by police.

With no place to go, the family slept in the car – except for the family dog. The police made provisions for Sheeba.” Christine said, “That was the part that I think came out in the eviction. When they came for me at three in the morning, they didn’t have a place for me and my family to go, but the animal shelter came because they knew that there were dogs there” (Glaude, 2016, p. 14-15).

Christine’s story conjures a compelling question: what type of society do we live in that has a place for helping dogs, but no room for helping the Christines of this world?
Religion can be one of the most potent tools for helping society's disinheriteds regain their humanity. Good religion insists that all humanity be able to assume their rightful place in the human family. In the words of Walter Rauschenbusch, “The religious spirit removes mountains and tramples on impossibilities. Unless the economic and intellectual factors are strongly reinforced by religious enthusiasm” social movements for transformation may prove abortive (Rauschenbusch, 1957, 5).

Religion can be a powerful force for healing the human family, first, because it requires the recognition of the inherent value of the human being. Dr. McIntyre’s presentation covered this subject well.

Second, religion can be an important force for healing the human family because having established the value of the human person, it demands that the personhood of the human be protected through social justice. Here, the spirituals of my slave ancestors – perhaps the most comprehensive black theological treatise – is an instructive source. In the spirituals, the slaves’ ultimate concern (freedom from degradation) is brought face to face with their beliefs about ultimate being (God), and the resolution is their emphasis on their inherent worth in the face of their oppressors, “I know de Lord Laid his Hands on Me.” They theologized about human equality and the unfulfilled promises of a democratic society when they sang, “I got a robe... you got a robe, all God’s chillun’ got a robe.” Based on human value and democratic equality they condemned the injustices of their society and prophetically imagined a more just social arrangement. Such an arrangement requires what Thurman called, “A social order in which even the weakest may find refuge and refreshment” (as cited in Fluker & Tumber, 119).

Lastly, religion can be a transformative, reparative, and healing tool because it requires a society arranged with what womanist religious scholar Keri Day calls “a politics of love.” She says, “In this neoliberal moment, love is seen as apolitical and unrealistic. Love is often used in confusing and sloppy ways, which leads to a disbelief in love itself.” However, “The analytical and political importance of love must be grappled with because love is a concrete revolutionary practice that makes room for an affective politics needed to resist neoliberalism” (Day, 2015, 105).

Love is not mere sentimentality. It is not and could never be passive. Love is the most compelling force available to the human family because it is about promoting and protecting the most foundational aspect of human existence – being itself. As Tillich writes, “Life is being in actuality and love is the moving power of life. Being is not actual without the love which drives everything that is towards everything else that is. In [humanity’s] experience of love the nature of life becomes manifest” (Tillich, 1960, 25). Consequently, love cannot be passive, but is the very foundation of power in and through which justice is created and human flourishing is made possible.

Conclusion

What is necessary to repair the human family from the ravages of poverty is a socioeconomic-political love that affects the ways in which we organize society and value humanity. As Day writes, “Without love, political communities are unable to engage the profound importance of neighborly care, no matter who that neighbor may be, which forecloses possibilities of a truly just society” (Day, 2015, 107). The words of the Apostle Paul caution people of faith, reminding us it may not only be that “though we speak with the tongues of men and angels and have not love, we are clanging symbols;” but, also though we have welfare programs, charity, and fine institutions of social aid and fail to have a society founded on the political practice of love, then we are all wasting our time (1 Corinthians 13:1).

References


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Equitable Health Care to Minorities: An Ethical Dilemma Complicated by Corporate Profit and Misinformation

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Author Note
This discussion brings forward critical issues impacting the health and welfare of minorities in the US through an in-depth analysis of past and current health care practices that are further impacted by unclear, convoluted, and deceitful advertisement in print, online, and TV. The analysis showed that there is plenty room for improving public health to minorities via clear information and equitable services. The content of this paper was presented in part at the 2016 Public Health Ethics Forum entitled, “Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection for Social Justice,” at the Centers for Disease Control and Prevention (CDC) in Atlanta, GA, on April 22, 2016. The authors declare that they have no potential or actual conflicts of interest or investments in any of the organizations cited. The authors acknowledge support from Tuskegee University, CDC, the National Center for Bioethics in Research and Health Care (NCBRHC), and The Dominican Republic Ministry of High Education Science and Technology (MESCyT).
Abstract

As a developed nation with high expenditure for medicine, the US lags behind other developed nations in equitable public health care serving minorities. This is because initiatives, policies, and procedures are based on for-profit business models rather than benefits to humanity. Even with budget, research, drugs, and bureaucracy to dispense services, the US fails to effectively inform and treat all of its citizens. Affordable prevention is not a part of the US health care business, and minorities are most adversely affected. Minorities in underdeveloped countries such as the Dominican Republic benefit more from targeted (social justice) information than those same minorities in the US. The US’s overly-complex health care administration is run more like a business, and does little to balance treatment-repair solutions with targeted mitigation and prevention. Witnessing the negative impacts of selective public health services stratified by income is disheartening. Confusing messages in print and TV further serve to mystify the matters around healthcare. The dichotomy between what the afflicted and the provider understands is revealing: A 2011 Consumer-Reports survey showed that 37% physicians but 79% of patients believed physicians managed their pain properly. Inform-consent should drive equitable delivery strategies rather than policies alone. Critical for national growth, minorities must be protected and receive clear messages about nutrition, prevention, and medical products that point the way toward equity.

Keywords: Education, Minorities, Hispanics, Latinos, Prevention, Medicine, Health Care, Social Justice, Equity-Equality, Nutrition, Obesity, Policies, Misinformation, Convoluted Messaging, Profits

Introduction

It is fitting to begin this work by reminding readers how significant it is to use critical thinking (common sense) in the interpretation, application, and/or heeding instructions regardless of the information source. A friend recently indicated that he had been taking a daily baby aspirin as recommended for post heart surgery. He also mentioned he could not keep his balance without holding onto a solid object. Cesar Fermin having conducted his graduate and postdoctoral studies plus several decades of inner ear research specifically in balance and equilibrium, told his friend that he needed to stop taking aspirin for a while, because one of the side effects of its active ingredient or “salicylate” is loss of balance. Despite explaining the metabolic and physiological reasons for his imbalance he continued taking the daily aspirin because his doctor said so, and several years later he is still unable to balance without holding onto something. While aspirin can be a miracle medicine, taken without buffering and careful monitoring it can cause gastric bleeding and the above. In the inner ear (not the external), plus several other places such as the bursa (fluid-filled sac) that offers cushion to joints, salicylates are “only” recycled (turned-over) very slowly sometimes >24 hours. Hence, continued salicylates’ ingestion saturates (concentrates) them in these places enhancing (potentiating) their action. There are many other such cases of medicines that while indicated for good reasons, also have secondary side effects that can cripple those to whom the recommendation was, in good intention, meant to help. Thus, begins the discussion of emphasizing the importance of good intention, meant to help. Thus, begins the discussion of emphasizing the importance of good intention, meant to help. Thus, begins the discussion of emphasizing the importance of good intention, meant to help. 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AARP described and presented potential solutions for avoiding the above errors by highlighting problems with the US health care system. With this type of reporting AARP, Consumer Reports (CR), and other consumer advocacy groups have consistently exposed significant gaps in the US healthcare information and proposed potential “simple” solutions that generally were unchecked or ignored because of their potential negative impact on bottom line profits. AARP and CR, in plain language with concise recommendations help to mitigate errors, avoid scams, and discern misinformation. Consumers most often receive those warnings and information through “flashing” disclaimers on TV or impossible to read small prints. Products and services are driven by profits rather than benefits to humanity. This is an infraction to social justice that pundits and industrial magnates generally manage to dispel. Provost Fermin and Vice Minister Sanchez_Cardenas participated at the Tuskegee University National Center for Bioethics, Research and Health Care (NCBRHC) conference at CDC the 2016 Public Health Ethics Forum - Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection for Social Justice. The program between MESCyT and TU is significant in its relation to the topic of this paper because indirectly the Dominican Republic has had to address literacy issues at its border with Haiti impacting citizens in these countries, the Caribbean Basin, and The Americas in general. The CDC presentations explained Tuskegee University’s Mission & Purpose of the Public Health Ethics Forum celebrating the life and work of the founding principal/president Booker T. Washington (Washington, 1995), who in 1915 founded National Negro Health Week that is now expanded to all, including Hispanics.

Prevention, Freedom, or Treatment – Reasons Behind Dichotomies

Entrenched Commodities of Western Medicine: Nutritional guidelines with breakdowns for calorie intake abound for decades in many textbooks (Fayard, 1956), brochures and pamphlets (Lilly, 2000), but these materials are not readily available in places minorities may frequent or for that matter printed in language or format that minorities can understand. Meaningful information that provides useful tips to manage one’s health and prevent dozens of ailments is difficult to find in places that low-income minorities (Fig. 3) frequent (e.g.: grocery store, dollar stores, delis, churches, etc.). Moreover, Internet sites with sufficient information to discern between misinformation and plain truth may not be available, or non-specialists may lack the knowledge/skills needed to use these tools for accessing the information. Even when information abounds in textbooks; they are rarely available to minorities, and even if they do have access to them, they are often not written in a sufficiently plain language to be of help. This lack of information seriously handicaps minorities and low-income citizens when it comes to choosing a treatment plan. Despite physicians’ clear understanding of the etiology-diagnosis-treatment cycle of certain diseases, many of them worsen after the external interventions preferred by western medicine approaches. Her work in New Orleans which began in 2005 immediately after Hurricane Katrina (Imelda K. Moise, 2016), influences the social justice work she continues today.

The progress made by the current Dominican Republic administration speaks volumes about “demonstrable” results from investing in educating the masses through an equitable program with altruist intentions for all (social justice). It also speaks volumes about putting resources and equitable social justice policies behind rhetoric. Provost Fermin and Vice Minister Sanchez_Cardenas participated at the Tuskegee University National Center for Bioethics, Research and Health Care (NCBRHC) conference at CDC the 2016 Public Health Ethics Forum - Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection for Social Justice. The program between MESCyT and TU is significant in its relation to the topic of this paper because indirectly the Dominican Republic has had to address literacy issues at its border with Haiti impacting citizens in these countries, the Caribbean Basin, and The Americas in general. The CDC presentations explained Tuskegee University’s Mission & Purpose of the Public Health Ethics Forum celebrating the life and work of the founding principal/president Booker T. Washington (Washington, 1995), who in 1915 founded National Negro Health Week that is now expanded to all, including Hispanics.

Figure 2. Currently the greatest epidemic obesity matches the geographic distribution where the poorest live, work and survive. In some areas of the map such as in Macon county where Tuskegee University is located, access to prevention is minimal and worse to affordable health care.

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diseases mirrors advances in the industrial revolution and replacement of natural and preventive healing with halting (not necessarily curing) with synthetic and often patented drugs. To escape the convoluted messages in drug advertisements that push unsuspecting individuals to choose their treatment over natural or cost-effective healing, one must turn to unbiased sources of information. One such source is Consumer Reports, which Fermin has subscribed to since 1981 (no financial interest in the service). Shortly after reading the 1980 edition of the “The Medicine Show” (Consumer Reports, 1980) that reported in 1981 a prevalence of “...575 different tablets, liquids, powders, lozenges, gums and pills compete to soothe our stomach complaints” as we continue even today to increase the number of chemicals needed to extend shelf-life sacrificing health benefits in wholesome foods “...the number of chemicals added to food is now so large, that it is said a Thanksgiving meal will provide a thousand chemicals” (Buchman’s, 1980).

Decades old health atlases, encyclopedias’ drawings, and text books dedicated to nutrition did a much better job presenting complex information into easy and understandable concepts for the non-specialist (Ratcliff, 1975). In the 1956 book by (Fayard, 1956) simple tables illustrate the differences in body frame-types, and their importance for calculating daily intake and calories needed for each type. In today’s explosion of net-information, understanding the significance of different human anatomy body frames in relation to body mass is not simple. Worse, recommended daily intake, also known as RDI, is still based on the 1968 calculations with few tweaks (Wikipedia, 2016a). The problem is that even educated scientists have difficulty matching tables with values for micro-nutrients in foods (Wikipedia, 2016a), and with information printed on food labels and that is required by federal agencies.

Take for instance, the number of calories burned by using an upright bicycle for 10 minutes at mid speed: ~50. Now note that an 8-ounce cup of an average sports drink, made with high fructose corn syrup, provides sufficient fuel for the human body to make over 100 calories. Any food (also known as fuel) that is ingested will be processed. If calories are not needed they will be stored as fat (Fig. 4). A pound of fat fuels nearly 4,000 calories. Do the math for how long it will take the body to remove that pound of fat using the upright bicycle.

Figures 3 and 4. Shelves from a Macon county discount store where despite being a large rural crop-growing region, colored sugar water surpasses healthy home grown vegetables, fruits and other produces. None of the containers on this shelf is 100% juice with natural fructose, and the minerals and vitamins therein. Rather, the ingredients are water, high fructose corn syrup, color, and preservatives.

Figure 3.

In this documentary “Fact, Sick and Nearly Dead” the before and after photos of the author corroborates the resilience and magnificent power of the human machine if only provided with the fuels it was designed to use. Originally taking 16 pills daily and given one year to live by his physician, a “simple natural” nutritional regimen plus exercise returned him to normal in less than 2 years.

Figure 4.
This example illustrates the need for education and plain-language information for the most vulnerable of our society. Hoping that low-income minority citizens locate, pay for, and read consumer advocacy publications such as Consumer Reports or AARP publications is not an efficient or realistic way to inform the public. Citizens paying taxes that support the US Public Health System (PHS) should not have to wait for non-governmental publications to decipher the dangers of advice given to patients by health care providers. Instead, useful information is often reserved for or targeted to the wealthier members of society who are capable of purchasing any health care service they need to mitigate any condition.

Judging from a lack of clarity in the manner that products intended for “oral consumption” (that is ingested) are introduced and advertised, and given that even trained, educated, scientists have trouble understanding the reasons behind the push to purchase drugs and junk foodstuff, it is reasonable to assume that average consumers do not understand the dangers behind the consumption of the products being pushed. It is to the advantage of big business and advertisers to keep it that way. For the US to catch up to other developed nations in preventing serious illness, it must equitably educate all its people taking into consideration the benefits of a healthy working society. Currently, it seems profits from health care services are more significant to the US than preventing diseases with huge impact on the national economy. Minorities must demand educational opportunities at all costs to avoid falling prey to big business for profits initiatives, deceitful advertising, and plainly inhumane tactics.

Equitable Activism

Clinical and community delivery systems for preventive care (Alex H. Krist, 2013) have been discussed, but the current performance-assessment and reimbursement-initiatives for preventive services centers on administrative matters rather than impacting the behavior and customs that lead to disparities. For this approach to benefit the needy, federal policies and programs need alignments that are sure to be resisted in the future. Judging from opposition to the Affordable Health Care Act (Obama Health Care), we can expect more pushback among social justice initiatives. In general, it is less profitable to prevent than treat. For instance, a 200-bed hospital could employ or deal with thousand components and personnel from: “a) Manufacturer representatives, Marketing companies, political pandering multitude of federal agencies, technical, clerical and administrative staff, board of directors, consultants, departments, field investigators, attorneys, insurers, broker groups, physicians, nurses, technicians qualifying for a typical business enterprise built to repair or fix your broken body not to prevent it” (Allen, 2004).

As a beacon of hope to humanity for over a century, Tuskegee University has consistently and intently defended the afflicted, provided opportunity for the discarded, fed the hungry, cured the sick, increased resources available to the poor, and advocated for human equality before, during, and after the Civil Rights Movement. As a part of this continuum, the Tuskegee University National Center for Bioethics in Research and Health Care in partnership with the Centers for Disease Control (CDC) in Atlanta presented a Public Ethics Forum entitled “Making Latino/Hispanic Health Count: Advancing a Public Health Ethics Framework on Data Collection for Social Justice” where the ongoing worsening health conditions of minority populations including Hispanics was examined. This Forum about Hispanic health inequities followed similar discussions on African American inequities in 2016 demonstrating that year after year the problems of inequality and social injustice continues to intensify.

Analysis of the inequality topic demonstrated above, among other things, shows that the worse un-intended consequence of convoluted messages is seldom anticipated, or for that matter, discussed, in the decision-making process that leads to the action-message in the first place. Latinos, like African Americans are suffering consistently from cardiovascular diseases and obesity at a much higher rate than whites. While the triggers for a majority of cardiovascular disease-related illnesses in minority populations is not a simple problem to expose, there is sufficient information from scientific experiments and anecdotal accounts to suggest that poor, unbalanced nutrition is a major contributing factor to the inequities that lead to the worsening health disparities emerging around the globe. Yet, the disparity between minorities and whites’ suffering due to inequitable care delivery is NOT for a lack of healthy foodstuff, rather an abundance of junk foodstuff pushed through advertising, convoluted messaging, buried information, and plain disregard for humanity in favor of profits. In lieu of what we know about the variables contributing to these disparities, and inequities, one is left to assume that the current health care system benefits from a population that is always in need of medical attention because as Dr. Allen (Allen, 2004) suggested “A Cure Is Not Welcome.”

This is not to say that the current medical delivery system is useless, but to highlight that it does not optimally deliver quality, affordable products equitably. While the pandering of unbalanced or junk nutritional foodstuff (fuel) by industries continues, the government may be powerless per constitutional amendments. What is said and how it is said is up to legalese not necessarily “all facts” (FDA, 2016). Vioxx is a good example of a product that the FDA approved, passing all requirements of laws, before being taken off the market due to safety concerns—its side effects proving worse than the ailments it was purported to heal. Unfortunately, in cases like this, the responsibility for discovering and reporting on the potential harmful impact of consuming a bad product generally fall to private watchdog groups.

Nutritional Misinformation

In an intentional drive to switch people from wholesome foods that needs preparation shortly after harvesting to those with long-shelf-life, big business had to find inexpensive means to: 1) keep organic foods with large water content looking good, or 2) keep bacteria and other pathogens from growing in or with them. Enter fat, salt, and nitrates without which water to safety concerns—its side effects proving worse than the ailments it was purported to heal. Unfortunately, in cases like this, the responsibility for discovering and reporting on the potential harmful impact of consuming a bad product generally fall to private watchdog groups.
lead minorities to accept a two-week treatment that will “certainly” lead to intestinal flora decimation. In turn, the above requires multiple drug interventions to address problems caused by side effects (e.g., constipation, flatulence, etc.), while the “original clinical presentation may be masked rather than resolved.”

When we consider how the current medical system has no qualms destroying a patient’s intestinal flora to achieve the goal of resolving an infection elsewhere, it is not surprising that inflammatory bowel disease also known as IBD has become a major health problem in the United States (Saban, Mathews, DeVon, & Janusek, 2014). For a patient to seek alternate means to re-build the intestinal flora after antibiotic treatment, rather than for the health care provider to match the prescribed antibiotic (ConsumerReports, 2016a) treatment with known means to rebuild the G.I.’s flora is a disservice to humanity. An abundance of drugs choices to address secondary effects after primary treatment is a deplorable practice. Even a mid-level medical trainee should understand that spikes in body temperature of less than 2 degrees centigrade for short periods and during an infection are a body’s natural defense against whatever is causing the infection, and that if such spikes are not “sustained” above 2 degrees centigrade for 48-72 hours with discharge (pus, bloody sputum, etc.) more careful evaluation should be contemplated before indicating antibiotics.

Every human is born with two strong surveillance internal systems driven by lymphocytes with strong sensitivity and memory to remember intruders: 1) One has preferred residence in the bone marrow - general blood circulation, and 2) while the other has preferred residence for the gastrointestinal track (mouth to anus). Anyone with intolerance (e.g., lactose in milk) or allergy (e.g., nuts) to certain foods understands this well without a need for medical training. Agencies protecting the public base approval and safety warnings on scientific design requiring statistical analyses (Morulsky, 1995) of more than seven individuals (subjects) before a “significant” or valid result if approved by FDA. However, approvals may lack companion policies for helping the underrepresented in favor of practices that while lawfully applied remain vague and full of loop-holes (ConsumerReports, 2012). Nevertheless, despite this well-known fact in scientific publications about the requirements for synergy between the surveillance of the G.I. immunity and intestinal flora capacity to process nutritional substances (e.g., absorption of nutrients, vitamins, etc.), the connection is seldom made unless the patient knows the triggers leading to intolerance or allergy. Refined oils (oils mixed for higher boiling point) currently mass-produced and used in most public places to cook food for low fees (fast-foods) may have contributed to explosion of G.I. related ailments. Unfortunately, refined oils are not drugs. They are raw materials mass-produced in third world areas such as Indonesia, and may not be fully regulated. Warnings about foodstuff made in plants where nuts are processed is of not benefit to a person with palm oil intolerance, because palm oil is currently in 90% of processed foods in supermarket shelves. Like lactose and peanut, intolerance to palm oil is very serious but is seldom flagged. There are not warnings on any oil refined mixtures from or with molecular relatedness to nuts for alerting intolerant individuals about potential connections with their symptoms (e.g., distended abdomen due to excessive gas), and abdominal pains due to inflammation, etc. (CDC, 2016).

Hence, an indirect relationship between acute G.I. conditions and persistent “intolerance” response to foods fried in such oils is probably significant for the health “prevention.” Yet, patients only find out after countless assaults, or alerts from Internet forums. The active G.I. mucosa repair mechanisms attempt to correct persistent immune responses. However, the capacity to repair eventually falls short and cellular and tissue transformation (latent or active inflammation (Alexander, 2016) may lead to chronic conditions such IBD, etc., or more irreversible changes leading to cancer (e.g., colon). The best demonstrable evidence for similar transformation by external agents (drugs) leading to cancer is emphysema (Escolar et al., 1995) caused by smoking. Recall that our lawmakers testified (swore) under oath that smoking, cigarettes (Fig. 5), or for that matter nicotine, tar, the approximately 3,000 chemicals in tobacco...
Without effective education, it is very difficult for minorities to understand the underlying complexities of the health care providers’ business in retaining a significant user’s base profit. Without a paid subscription to helpful sources such as Consumer Reports or using controlled (commercially or medically) substances, but private independent outfits that do the best job exposing the charade of public health information made possible by laws enacted through lobbying effort of big business.

Prevention vs. Pills

One of the biggest issues plaguing western medicine’s delivery of service in the US is big business’s negative impact on equitable initiatives. Take for instance Obamacare, those who could not afford health care before can now benefit from: expanding Medicaid, forcing insurers to cover those with pre-existing medical conditions, or allowing young people to stay on their parents’ policies until age 26, etc.” (www.theweek.com). As a personal user of Obamacare, Caroline Fermin has been a direct recipient of these expanded social policies. As one of the country’s top dancers, traveling the world, working full-time, and using her body in extreme ways, she still found herself unable to procure health care. Utilizing the benefits of Obamacare allowed her to participate in the right to health care that her more wealthy friends already enjoyed. Despite these developments, which positively benefit minorities and low-income citizens, the inconvenience of the wealthy is what has been highlighted. The pushback against Obamacare has been loud, relentless and effective. It is only a matter of time before big business successfully revokes some of these reforms. In fact, it has already begun. Without accessible care for all, the cycle of misinformation continues. There is an absence of easily understood information that would allow minorities to comprehend how and what to supplement and under which specific conditions to do so (Claire N. Krukowski, 2016).

There is plenty of information in peer-reviewed and general publishing outlets showing that the human body is like a low voltage battery that requires a certain level of direct electrical current to operate (Carter, 1983). Eastern medicine successfully tapped into this logic and developed and used means to modulate strength and flow of biological current through acupuncture, reflexology, or other noninvasive means. Old fashioned home remedies, detoxed and not recommended in western medicine, have been proven effective in eastern medicine for centuries (ConsumerReports, 2016b). Despite thousands of years of literature on the subject, and the fact that many ailments could be delayed or potentially reversed through acupuncture or herbal remedies, the best an alternative-seeking patient can do is receive a primary care physician’s referral for physical therapy treatment, that being the closest option to the above. This further emphasizes that only a business designed for “repairing” is “lawfully” capable of providing the desired relief. Thus, patients of limited resources seeking alternative healing, discover that most are not supported by western medicine (Cummins et al., 2015). Patients often find themselves arguing with a staffer with zero knowledge of a disease about eligibility for coverage that has been clearly understood by the seeker as being beneficial from prior experience. From the standpoint of social justice, this example serves to illustrate the current state of affairs of the medical business we must use.

Despite thousands of years of literature on the subject, and the fact that many ailments could be delayed or potentially reversed through acupuncture or herbal remedies, the best an alternative-seeking patient can do is receive a primary care physician’s referral for physical therapy treatment, that being the closest option to the above. This further emphasizes that only a business designed for “repairing” is “lawfully” capable of providing the desired relief. Thus, patients of limited resources seeking alternative healing methods come face to face to the reality that most these methods will not be covered by most health care providers (Cummins et al., 2015). As a professional dancer-athlete with over 25 years of high-level training and expertise, Caroline Fermin can attest to the fact that a person with this type of career could not possibly stay healthy utilizing current government guidelines and recommendations. Taking a daily Advil at the age of 25 was the only “cure” offered by a Primary Physician for back pain—that, or to quit exercising. Instead of settling for this half-truth, Caroline Fermin located an acupuncturist, an Alexander Technique specialist, and heeded a low-inflammatory diet (Alexander, 2016). These non-conventional, but ultimately very successful, interventions took time, research and trial and error. How can this be the best way to ensure effective cures?

Electric currents’ strength and flow are impacted by a multitude of external factors, among them magnetic and other waves invisible to the human eye. Internally, the efficacy of the electric current depends on an elaborate set of reactions that require some “inorganic” elements absorbed by plants and animals we eat. Like a car battery needing lead (solid) and acid (fluid) to retain and transfer a charge, each cell in tissues or circulating through the body also need solids and fluids to balance energy. This has been known for millennia as the key to “functional harmony” of the body, as explained by Larry Clapp (Clapp, 2013). “Unlike the energy, we use to power and to run our cars, the universal energy force is self-sustaining” a principle that guides eastern medicine and is ignored during treatment by western medicine. The sophistication of the human body’s operation is such that a majority of interventions used in modern medical practice disrupt that essential energy or its balance. Dancers and athletes have long known about this balance and practiced self-care that centers around the idea of sustaining one’s “life-energy.” The delicate balance between the energy one wants to access and the energy one currently has can be mitigated and directed through the foods ingested and the health practices one engages in. This holistic practice of looking at the “whole” instead of the parts is what enables athletes to remain at high levels of peak functioning and health (Alexander, 2016; Dietzel, 2016). Helping the average citizen to understand health in this way enables them a degree of personal control and an understanding of prevention. However, as stated in the abstract, even with budget, appropriations, research, drugs, and bureaucracy to dispense services, the US fails to effectively inform and treat its citizens, because affordable and accessible prevention is not a part of the US health care business.
The confusion surrounding healthcare information and policies is well explained in a report in *Time* magazine “One way to cure illness is with pills and procedures. Another is not to get sick in the first place” (A. Park, 2009). While the article lists helpful tips, it is sandwiched in between numerous ads from drug companies. Just in this one volume, readers could choose from: pages 9-12 (AstraZeneca –PAR Pharmaceutical) for TOPROL-XL, with these side effects: tiredness, dizziness, depression, diarrhea, itching or rash, shortness of breath, myocardial infarction, Pneumonia, cerebrovascular disorder, chest pain, aggravated tachycardia, diabetes mellitus abdominal pain, fatigue, and slow heart rate; pages 19-20 (Park Davis a Pfizer Labs Division) for VIAGRA, with these side effects: headache, feeling flushed, and upset stomach, trouble telling blue and green apart, eyes being more sensitive to light, blurred vision, sudden decrease or loss of sight, sudden decrease or loss of hearing, heart attack, stroke, irregular heartbeat, and death; pages 40-42 (Bristol-Myers Squibb, Otsuka America Pharmaceutical, Inc.) for ABILIFY with side effects: Nausea, vomiting, constipation, headache, dizziness, and inner sense of restlessness, akathisia, anxiety, insomnia, stroke, high fever, muscle shaking, confusion, facial twitching, increase thirst, increase urination, faintness, and dysphagia; pages 65-66 (Pfizer Labs) for LIPITOR with these side effects: weakness or pain, nausea, vomiting, stomach pain, dark colored urine, headache, diarrhea, gas, rash, or constipation; pages 91-92 (Merk Schering Plough Pharmaceuticals) for ZETIA, with side effects: pains, feeling tired, muscle breakdown resulting in kidney damage, swelling of the face, lips, tongue, and/or throat, breathing difficulty, rash, hives, liver problems, inflammation of the pancreas, nausea, dizziness, tingling sensation, depression, gallstones, and inflammation of the gallbladder. These adds illustrate publishers’ need for profit combined with the lure of drug makers to sell their products.

Even federal agencies may skew messages by discouraging cures proven to work for centuries, favoring drugs until companies’ design, pay for tests, and obtain approval. In “Medical Botany: Plants affecting Man’s Health” the authors (Elvins-Lewis, 1977) cited gout as a good example with known triggers from food with high purines content, and worsening of gout that western medical practice treats (whether inherited or not) with drugs rather than with naturally occurring substances or preventive measures (found in spices and foods). Food therapy has been around for centuries (Prevention, 1995), effectively used by ancient Sumerians, Assyrians, etc. and documented in ancient scrolls, but in the west “...When Henry Ford started turning power tractors off the assembly line in 1905, the American diet started to change—and as a result, so did the health of Americans...The reasons why so many of us are sick and stay sick is nutritional imbalance...” that robs the cells of needed fuel or impact cells capacity to repair (Reavely, 1998).

Effective prevention messages moving forward should be converted into understandable concepts. As science continues to dismantle the complexities of the human body with its billions of nano-factories (cells and organelles), data is emerging showing that the cells and internal nano-factories can self-repair given time (when appropriate). Furthermore, the needed molecules to fuel these metabolic processes are cited in a recent paper (David, 2015), which suggests that mitochondria in muscles of elderly mice were restored to a youthful state after the naturally occurring molecule Nicotinamide mononucleotide effect. This molecule is the fuel for mitochondria to light the fire that moves most living things. The potential rejuvenation observed was not through western medicine’s approach, flooding muscles with substances of known acute side effects, but rather by activating the cell’s innate ability to self-repair.

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The confusion surrounding healthcare information and policies is well explained in a report in *Time* magazine “One way to cure illness is with pills and procedures. Another is not to get sick in the first place” (A. Park, 2009). While the article lists helpful tips, it is sandwiched in between numerous ads from drug companies. Just in this one volume, readers could choose from: pages 9-12 (AstraZeneca –PAR Pharmaceutical) for TOPROL-XL, with these side effects: tiredness, dizziness, depression, diarrhea, itching or rash, shortness of breath, myocardial infarction, Pneumonia, cerebrovascular disorder, chest pain, aggravated tachycardia, diabetes mellitus abdominal pain, fatigue, and slow heart rate; pages 19-20 (Park Davis a Pfizer Labs Division) for VIAGRA, with these side effects: headache, feeling flushed, and upset stomach, trouble telling blue and green apart, eyes being more sensitive to light, blurred vision, sudden decrease or loss of sight, sudden decrease or loss of hearing, heart attack, stroke, irregular heartbeat, and death; pages 40-42 (Bristol-Myers Squibb, Otsuka America Pharmaceutical, Inc.) for ABILIFY with side effects: Nausea, vomiting, constipation, headache, dizziness, and inner sense of restlessness, akathisia, anxiety, insomnia, stroke, high fever, muscle shaking, confusion, facial twitching, increase thirst, increase urination, faintness, and dysphagia; pages 65-66 (Pfizer Labs) for LIPITOR with these side effects: weakness or pain, nausea, vomiting, stomach pain, dark colored urine, headache, diarrhea, gas, rash, or constipation; pages 91-92 (Merk Schering Plough Pharmaceuticals) for ZETIA, with side effects: pains, feeling tired, muscle breakdown resulting in kidney damage, swelling of the face, lips, tongue, and/or throat, breathing difficulty, rash, hives, liver problems, inflammation of the pancreas, nausea, dizziness, tingling sensation, depression, gallstones, and inflammation of the gallbladder. These adds illustrate publishers’ need for profit combined with the lure of drug makers to sell their products.

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decades later, this time with High Fructose Corn Syrup (HFCS). Instead of nicotine that was commercially and mass-produced for-profit, we now have HFCS, the main cause of excessive empty-calorie products lacking nutrients, vitamins, and minerals that cells need for beneficial body-building functions.

Several documentaries from NetFlix are not only revealing, but worrisome in exposing big ‘business’ plan to suck profits from the poor, disadvantaged, and disproportionately targeted. Most revealing are: *Fat Sick, Nearly Dead; Fed Up; and Forks Over Knives*: on the power of the human body for self repair, when junk-food and drugs do not interfere with magic of its internal working power plants (cells nanomachines), Sugar coated: on the secrets of sweeter production, Poverty Inc.: on the convolution of rules toward perpetuating the work force dependence in support of big business profits, Fast Food Chains, Super SizeMe; Farmageddon75; and Food Inc.: on the grip the industry (big business) has in maintaining profit margins at any cost including human heath, More than Honey, on the detrimental effects of empty calories by HFCS (sugar water without mineral/vitamin) even to insects (bees).

The significance of clear truthful information was highlighted by Booker T. Washington in his biography: “Most people, I think, are able to draw proper conclusions if they are given the facts in an interesting form on which to base them.” This is a far cry from the manner in which big business pushes misleading information in print and TV. Today’s misinformation enforces wrong attitudes and behaviors described by Booker T. Washington in this humorous but sad interpretation: “In fact, one of the saddest things I saw during the month of travel which I described was a young man, who had attended some high school, sitting down in one room cabin, with grease on his clothing, filth all around him, and weeds in the yard and garden, engaged in studying French grammar.” For minorities, then and now it is critical that public health policies should rest on clear, effective, and targeted information.

**Equity and Equality:** Understanding the plight of the poor is not the forte of the elite with education, power, and money. Fig. 6 shows the humble beginning of Cesar Fermin’s home while in K-12 with no running water, no sewage, electricity, or food in the Dominican Republic. At the time, this undeveloped country (Aquino García, 1996; Fortunato, 1998; Vargas Llosa & Grossman, 2001) had just emerged from Trujillo’s dictatorship, but was still a significant contributor to the sugar cane industry to the Americas. Enter HFCS not only as a significant contributor to diabetes, but also as one of the primary reasons for devaluation of the country’s currency and with it decreased support to the poor. Not because before, governments and juntas cared for the poor, but because at least the poor could eat the crumbs (Coates, 2016) left behind by the rich as they enjoyed the high value of the currency against the dollar. In the US teeth decay, can be helped with dental sealant, but how beneficial is this process to a minority whose bite needs sealants. The ability of the human body for self repair, when junk-food and drugs do not interfere with the magic of its internal working power plants (cells nanomachines) is fed by convoluted and deceitful advertisement.

When it comes to misinformation, minorities should understand that laws may not necessarily be enacted with their benefit in mind, and history has plenty to tell: from disallowing credit and dues to inventors (Skloot, 2010), incredibly twisted conspiracies (Haslam), intolerant masters (Colbourn, 1972), abusive and inhumane plays (Jackson, 1881, 2003), and undignified treatment (Gray, 1995; Hrabowski; Reverby, 2000b; Stevenson, 2016; Taper, 2003). Among the biggest losses has been a decrease in support for education leading to high illiteracy, malnutrition, and disease. High quality medical care has always been available to the wealthy, but an equitable public health system for social justice to the poor has always been hotly contested. Desperation for survival surpasses a desire or need for formal education, throwing populations into a vicious cycle of having to adopt temporary fixes rather than applying permanent and lasting solutions. Using this illustration (Fig. 7) one can clearly see that if the right of three spectators is to enjoy the game, ownership of the box matters little unless the shortest spectator buys the box from big business – Viagra or Cialis vs. L-Arginine parallel. Each spectator has a box but the tallest does not need it to look over the fence – hence the difference between equality and equity. Therefore, until the US can equitably provide for its citizens, wanted or not, it favors big business who can buy what it needs.
Despite being the strongest and richest nation, US minorities join an ever-increasing global poor population as data from the World Bank (Fig. 8) indicate.

More than Disparity - Dichotomy: The current medical practice, by necessity and skills gained during training, prefers purified chemicals pandered by pharmaceutical companies for the treatment of certain ailments; even though the industry knows well that the majority of purified compounds are “ineligible” to enter many cellular pathways or metabolic reactions to aid cellular repair. It is probably not for lack of understanding about the compounds’ actions (Physician Desk Reference or PDR and similar references make sure we know), but rather from putting into practice, skills gained during medical training that emphasized it. Below we address several examples (from hundreds published) that validate the need for medical training in the US to stop talking about prevention and practice it. As mentioned in the abstract, the dichotomy between what the afflicted and the provider understand is revealing: A 2011 Consumer-Reports survey (>50K members) showed that 37% physicians but 79% of patients believed physicians managed their pain properly. In the August 2016 issue (ConsumerReports, 2016c) that a survey in March 2016 indicated that 8/10 doctors expressed concern about patient’s ability to afford treatment, but only 2.6/10 patients said that doctors discussed the matter with them. Meanwhile, some physicians report that “...People with treatable conditions are not getting the relief they need, and they are dying taking the drugs their doctor prescribed for them.” In the case of back pain, the report indicated that pain should not be masked or ignored, but instead put through a battery of treatment options. This is because the pain is not something you can remove with drugs as the body is telling the patient that something is wrong, needing attention (ConsumerReports, 2016d).

Vasculature (Capillaries) Stiffness in Cardiovascular Disease: When taking a critical look at the hundreds of spams email users who receive daily pandering purchase of Viagra or similar sexually enhancing drugs (Cialis) one must wonder the reasons behind their commercialization. None of the messages through electronic or printed media tell any potential user why these drugs facilitate, enhance, and prolong erection. In fact, unless requested, a majority of pharmacies would remove the “FDA required information matching” (PDR Network, 2014) as to emphasize the intent of the pusher to keep users in the dark. In other words, misinterpretation by the user may outweigh the known side effects disclosed in package literature. The explosion in the production of Viagra and Cialis drugs was facilitated by the discovery of nitric oxide’s effect on the vascular endothelial cells (make up the walls of a vessels or tubes). The intricate and sophisticated metabolic pathways in each cell require specific
compounds to manufacture nitric oxide, and among them is the amino acid L-Arginine. Anyone who took biochemistry in college can understand how L-Arginine relates to nitric oxide. This amino acid plays an essential role in the body's ability to produce nitric oxide. Researchers discovered that the isoenzyme endothelial nitric oxides synthase forms arginine derived nitric oxide (NOS or eNOS) that is released by endothelial cells thereby contributing to capillary health including ability to deform without breaking (expansion that occurs during an erection) a requirement enhanced cardiovascular output needed to pump blood into sex organs. It turns out that in chronic renal failure (kidneys can not filter urine well), hypercholesterolemia, atherosclerosis, congested heart failure, impotence and diabetes L-Arginine is impaired, suggesting its critical role in vascular health. Chronic diseases cost US industry millions of dollars in days of missed work (Allen, 2004).

From the above one has to wonder why the medical community has not used an amino acid that has no known significant or detrimental side effects to help patients with cardiovascular problems. The answer may rest in profits: commercially synthesized analogues or derivatives of L-arginine are patentable whereas this simple amino acid is not. In essence, the medical profession has not followed scientific evidence available for over decades showing the significance these amino acids has toward cardiovascular health (both the amino acid and patented drugs produce headache). On the other hand, pandering for the sale of Viagra and Cialis continues through all media (printed, TV, and Internet) filling up electronic mail boxes with unsolicited pandering.

Not All Sweeteners are Created Equal: High fructose corn syrup (HFCS) is sweeter than sucrose or fructose. Sweet, naturally occurring sources such as oranges, pineapple, etc. contain minerals, vitamins and other factors essential for human health. The corn refiners’ industry keeps pushing the idea that sweeteners (see Sugar Coated documentary) are alike despite research showing that fructose is a superior nutrient to HFCS (Akgun & Ertel, 1981), and even the humble and naturally occurring honey, is a better alternative fuel for living organisms (Abdulrhman, El-Hefnawy, Hussein, & El-Goud, 2009; Samanta, Burden, & Jones, 1985). Yet, as is often the case in scientific research, much of the reporting matters “how a present is packaged.” This article (Richard Forshee, 2007) clearly illustrates that point by arguing that the impact of HFCS on obesity and diabetes is not significant. However, plenty of data shows that the rise in obesity coincides with the synthesis and commercialization of HFCS. And, just like in the case of the tobacco and smoking debacle of decades ago (Barrientos-Gutierrez et al., 2007; Bono et al., 1996; Martinez-Sanchez et al., 2010; Surgeon, 2006), the current mess with the pondering of sugar-water laden with HFCS is an example of how significant discoveries with tremendous potential to help humanity were driven into obscurity. In fact, until recently, TV adds purported that all sweeteners are the same. Other cases of “good” scientific discovery trashing is also troublesome. The case of Dr. Kilmer McCall’s attempt in 1969 to publish his findings about homocysteine contribution to atherosclerosis illustrates bias by so called experts (peers) in protection of the status quo. Three decades after repeated rejections of his work by peer-experts that did not agree with his discovery, the paper was finally published with a net loss of 30 years of potential benefits to patients suffering cardiovascular maladies. The difference between dichotomies we recognize today and reported in the past, is that we know today which substances poison cells even when they are pandered for solving “specific” issues (see the documentary “More than Honey”). Moreover, secondary side effects often surpass the condition being treated are well known by drug companies and the FDA before the drugs hit the market. Once on the market these drugs are essentially “approved” for experimentation on human subjects, unbeknownst to them. Thus, cures, preventions, and alternate treatments, without a seal of agency approval are useless as folk remedies, whereas approved drugs with “fully” unknown effects are marked safe for distribution to “hopeful” sufferers as the Vioxx mess described below illustrates.

The Experimental Infamous N of One (N=1): Despite every major discovery or impact beginning with a case of one (n=1) patient such as the first heart transplant, the industry fights “individual” accounts of successful treatments outside procedures approved for profit margin (e.g., Vioxx). In science, experiments must satisfy certain thresholds to ensure significance (validity) rather than random occurrence such as the chance of head/tail when flipping “one” coin resulting in 2 heads, 2 tails or one each. However, when flipping “2 coins” the chance of getting head/tail is 4 heads no tails or 4 tails no head, 3 heads one tail, 2 heads and 2 tails and so on. To decrease the chance that head or tail is NOT a random occurrence, averages from high number of tests must drive research. Next comes adopting low/high values that are acceptable

Figure 9. This article was begun with a discussion on how HFCS replacement for sucrose as a sweetener decimated the economy of many sugar cane growing nations, but in particular the Dominican Republic where Cesar Fermin was born. The case for HFCS’ effect on health (or contributor to other factors affecting health) serves to illustrate the manner in which scientific research data may be interpreted, and published. Supportive or not to HFCS’s impact on obesity, the fact remains that the fastest increase in obesity paralleled the replacement of sucrose by HFCS.
and “possibly” representing the actual occurrences in nature. The simplest approach to convince peers (experts reviewing applications) is to use a t-test (student test) that requires a minimum of seven trials, subjects, etc., in order to prove that results are not by chance. However, this is not a simple design adaptable to living, breathing humans subjects, as consenting is required but not necessarily obtained (Reverby, 2000a). Who and how a drug or procedure is tested for approval depends on a myriad of factors that often escape reviewers, even specialists, judging from the Vioxx case.

Our western medical system ignores outliers (results that do not fall within a range or chosen threshold). Thus, for a patient who has been his/her own test subject after having to endure years of intolerances or allergies, the clinical presentation at the time of examination may or may not fit published information that justifies a prescribed treatment recognized by health care providers or for that matter understood by the referring physician. Fermin’s father was diagnosed with Arthritis in his teens but it was not proven from 1965-1991 when he died from other complications. Judging from that N=1, plus the author own N=1 experience with persistent allergies and intolerances contributed to his father’s constant “joint pain” would have benefited from regular administration of Brompheniramine Maleate or another similar antihistaminic over-the-counter-drug. To the author’s knowledge, such a treatment was seldom recommended (see above discussion about low turnover of salicylates in the bursas). In cases such as these, newer, expensive drugs that increase profits may be prescribed (Allen, 2004; Trudeau, 2004). This is despite the fact that: there are all-natural, nondrug, and non-surgical cures; there are organizations, government agencies, companies, etc., spending billions of dollars to disprove it; and, all drugs have side effects whether tested as a N=1 or higher. Just like the smoking denial of the 1980’s we now have HFCS denials (Fig. 9-10) while treatment for reducing diabetes increases.

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Figure 10. Compare HFCS syrup and other sweeteners’ (not sucrose) expansion with the CDC’s curve for fast paced development of diabetes and obesity in the US and the world. In particular, note the year. Cesar Fermin arrived in the US in March of 1974 shortly after the explosion of HFCS production, when one Dominican Peso was worth $1.20 US Dollars. Today One US$1.00 is worth RD$40.00 pesos.
Articles

MESCY* The Dominican Republic

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Figure 12. As shown in Figure 10, strides were made despite political strife, civil wars, and grip on wealth by the upper 1% wealthy since sugar cane production dropped. The government through its agencies including "Ministerio de Educación Superior Ciencia y Tecnología enacted its plans to educate and care for its citizens with substantial resources, and mandate changes that are probably not easily implemented in US where states want federal subsidies.

Misinformation’s Disgrace or Intent Thereof: Principles guiding the affluent “I get it when I need it,” do not work for disadvantaged populations (Lao et al., 2015) struggling to survive on junk food or color sugar water. This is one of the main reasons why the current system favors the affluent. In its September 2009 issue Consumer Reports presented results from a survey to almost 38,000 subscribers comparing Health Maintenance Organizations or HMOs and Preferred Provider Organizations or the PPOs: 18% of the respondents complained that they had trouble getting to see a doctor in the HMO or PPO plan, and those in HMOs pay less for premiums than in PPOs. Yet the most interesting trend from that survey was the distribution of such services across the United States. Deciphering the coverage and extent of services from participating members, choice of doctors, percentage of those getting access, access to doctors’ billing websites and online services, and customer service, it is evident that the healthcare system is not designed for the uneducated and poor.

The current system is so biased toward providers that devices intended for use in humans can receive authorization by simply filing a $4000 set of forms. Regarding the use of many complicated and potentially dangerous devices, Diane Suckerman explains: “often, testing is only in the bodies of unsuspecting patients.” Because such devices are not tested before they come onto the market, there is no systematic way for the government, researchers, or patients to learn about problems with such devices, and there is not much the patient can do to protect themselves under the current system (ConsumerReports, 2012). It is not devices only that are dangerous to your health but also tests, because patients may not know why doctors recommend treatments (see salicylate example in the introduction). Unfortunately, healthcare providers don’t always agree on which tests are necessary and it is not unusual for an insured patient to beg a “clerical” health care provider to cover tests. Additionally, it is necessary to educate the consumer about the limits of tests (ConsumerReports, 2013), because as explained in this issue of Consumer Reports “…[the] risk of screening and over-treating harmless cancers or undergoing additional tests and procedures only to discover a test was a false alarm…” may continue as long as “…cancer screening remains stuck in a 1960s view of the disease.”

Merciful and Equitable Social Initiatives: Despite much technological, post-industrial revolution progress, there is an alarming gap between what agencies (supposed to protect consumers) instruct, and what is shared with patients for their choice of treatment (ConsumerReports, 2016e). For instance, in a recent experiment, Consumer Reports sent shoppers to pharmacies in more than 200 stores across the US and determined that for the drugs

Figure 13. Behavioral Risk Factors by the CDC Surveillance System shows in 2015 that a majority of adults affected by the diabetes epidemic (which is paralleled by Obesity) is congregated in the poorest southern states surrounding Macon county of Alabama where Tuskegee University is located.
in jail. Yet, as the Vioxx debacle shows, experimentation into demonstrating Vioxx’s efficacy and safety ended long after the FDA approved it, and long after hundreds of patients had in essence, served as test-subjects without consenting.

At Tuskegee University, we know about legal maneuvering that satisfies man-made-lawsful action within protocol. Take the infamous United States Public Health Service Study of Untreated Syphilis in the Negro Male experiment in which unsuspecting and trusting minority citizens believed in purported benefits. The misinformation and deceptive advertising is actually very similar to today’s pandering to viewers to “ask your physician” to use products with proven negative side effects. (ConsumerReports, 2016f).

Intentional or not, the perversity and unethical implementation of practices that favor the elite over the underrepresented is a blight in an otherwise wonderful land that we all cherish and will fight for. To comprehend how convoluted “man-made-laws” (Stevenson, 2016) have been used and are still used to the advantage of the elite with no regard for equity and social justice, one has only but to read Ta-Nehisi Coates’s piece in the Atlantic (Coates, 2016). Unfortunately, we are sure that just like many we know, you too know someone who will argue against the truth behind these documented facts – legal scams for those in power to exploit the poor as they are supported by man-made laws. It is understandable that even respectable citizens believed in purported benefits. The misinformation and deceptive advertising is actually very similar to today’s pandering to viewers to “ask your physician” to use products with proven negative side effects. (ConsumerReports, 2016f).

Figure 14. Conversely, Hispanics adult are scattered, but congregated in states that support migrant and working populations in states with large border contact with central and south America.

The main point of this paper is not to discredit the good work that integral, dedicated, and altruist health care providers offer to the needy. Rather, the intent is to clarify that big business’s investments are not for the good of patients, but for augmentation of the profit outlay. Little has changed over centuries on big business’s ability to remain in control of power regardless of diligence as explained in (Machiavelli, 2008) “...The difficulty of maintaining hereditary states accustomed to the reigning family is far less than in new monarchies; for it is sufficient not to transgress ancestral usages, and to adapt ones’ self to unforeseen circumstances; in this way such a prince, if of ordinary assiduity, will always be able to maintain his position...” That is to say that holding onto one’s property or investment is at the heart of discovery, marketing, and profitability. These are the values that drive our health care system, not necessarily the desire to alleviate human suffering as Dr. Allen (Allen, 2004) suggested in “A Cure Is Not Welcome.” Moreover, suffering endured by minorities corroborates the twisted and purposeful enactment of laws that favor big business. This is done by disallowing credit and earning to inventors (Skloot, 2010), incredibly twisted conspiracies (Haslam), intolerant masters (Colbourn, 1972), abusive and inhumane games (Jackson, 1881, 2003), undignified treatment (Gray, 1995; Hrabowski; Reverby, 2000b; Stevenson, 2016; Taper, 2003).

In this work, the authors present observations, and facts from scientific work demonstrating that intentional or not, profit-driven distribution of foodstuff could be easily balanced by simply presenting a truthful representation of what is being advertised, sold, or discounted. By plainly stating what the products really do to human health in the short and long term, patients can choose between products and their potential damaging effect to human welfare (Public Health). It is therefore fitting that examination of this important disparity issue emanates from Tuskegee University where with hard work, its founding principal/president, Booker T. Washington echoed repeatedly the unfairness of a system that demands much from those with little, and none from those with power and money. In his “Up from Slavery,” Dr. Washington highlights the “state-of-reality” about the system we share paving the way for “all minorities” to enjoy it. In his biography, he reminded minorities that big business’s interest is not social justice or equitable treatment: “The white man who begins by cheating the Negro usually ends by cheating the white men. That white man who begins to break the law by lynching a Negro soon yields to the temptation to lynch a white man. All this, it seems to me, makes it more important as the whole nation lend a hand in trying to lift the burden of ignorance from the south” where minorities continue to bear a heavy social burden. In addition, the trend continues as Booker T. Washington prophesized in his biography, that despite access to income-driven, stratified services, man-made laws will always create a distinction between races and colors. "We are to be tested in our patience, our forbearance, work perseverance, our power to enjoy the wrong, to withstand temptations, to economise, to acquire and use skill, in our ability to compete, to succeed in commerce, to disregard the superficial for the real, the appearance for the substance, to be great and...
yet small, learned and yet simple, high and yet servant of all.” A corollary to this is the struggle of minorities remaining submissive; enduring exploitation; being the target of misinformation; and suffering from despair that can be easily mitigated. In the few decades since The Civil Rights “proclamations,” ...minorities are expected to automatically bounce back from centuries of historical systemic inequities.

It is therefore the responsibility of elected officials and agencies to make available clear information for minorities with limited language, technical, and/or other skills to understand the meaning behind complicated recommendations, dangerous treatments that are often, and unfortunately, approved by agencies in charge of protecting them (Elliott, Haviland, Kanouse, Hambarger, & Hays, 2009). Furthermore, taking actions in favor of big business’s bottom line for the sake of economical advance should be carefully weighed with long-term consequences such as those illustrated by the destabilization of the Dominican Republic’s educational, monetary, public health, and infrastructure by substituting HFCS for sucrose. Not only has the production of HFCS with US government subsidy damaged the economy and human development of third world countries depending on sucrose for survival, but more importantly, it has lead to the current “global” obesity epidemic (Bocarsly, Powell, Avena, & Hoebel; Bock, Kanarek, & Aprille, 1995; Bray, Nielsen, & Popkin, 2004; Brynes & Frost, 2007; Glendinning et al., 1983; Hung, 1989; Kanarek et al., 1987; Kanarek & Marks-Kaufman, 1979; Kanarek & Orthen-Gambill, 1982; Lomba et al., 2009; Lomba et al.; Rupp et al., 1989). Fortunately, in non-comparable time spans, repressed nations continue to make significant strides as a comparison (Figure 15-16).

Intentionally or not, minorities will continue to fight the same uphill battle that Booker T. Washington fought to conquer the dignity he enjoyed. Excerpts from his biography “Up from Slavery” (Washington, 1995) illustrate the impending difficulties ahead of us: “...I used to envy the white boy who had no obstacles placed in the way of his becoming a Congressman... p 20...individual and race should get much consolation out of the great human law, which is universal and eternal...”
Figure 17. Now we return to the main topic of discussion for this paper, which is misinformation, convoluted messaging, deceitful targeted advertisement, or simply unclear delivery. Abundance may be a good thing but only if it leads to good outcome. In relation to abundance of foodstuff including fast foods or processed foods, what should the difference be between calories’ intake for the young and the old? When should established recommendations, and for which body type (small, mid or large frame) should intake change, etc.? When is supplementation not just desired but required? Is a person eating fast food exclusively three times daily to ingest the same amount of vitamins and minerals as the one ingesting the diet described in documentary Fat, Sick and Nearly Dead (Fig. 4)? Or, is some healthcare providers advocate that everyone gets everything needed from foods (e.g., three fast food meals daily)?

Figure 18. Despite minute blips in 2005 and 2011 data, obesity has steadily increased in the young and adult US population, while the amount spent on health care is the largest from within developed (high income nations) as classified by World Bank data as of 2016.

As the documentary, Poverty, Inc. (Fig. 19) illustrates minorities should expect more misinformation about the real drive behind modernization, industrialization, and comfort associated with processed foods in which purported benefits will always obscure detrimental impacts on health. This fact is demonstrated by the barrage of advertisements (Figures 20-21) that went from 2.1 to 4.5 million from 2010 to 2014 with Cialis leading the pack with a total of 275 million through 2014.

Figure 19. This documentary demonstrates the importance of education to decipher the true intent behind industrialized development that is purported to assist minorities. It is by now abundantly clear that big business’s intent is by necessity, to increase profits, not necessarily to help the afflicted. This includes rhetoric advising “healthy people” to ask prescriptions for new drugs (see Figure 20) or eat fast food instead of freshly cook meals.
Considering the wealth of the US, the infrastructure for research and development, and the cause-effect relationship that available data demonstrates, including billion of dollars earned by drug makers and distributors, minorities must remain vigilant not only about intent.

It is up to those in need of medications to understand the true intent behind marketing and deceitful advertisements with cloudy messaging and impossible-to-decipher side-effects. As discussed above for the Vioxx debacle, approval through "protocols" and by lawful process cannot guarantee healthy outcomes.

Minorities should expect to see stronger justification distancing HFCS from diabetes and inferences from industry supported research demonstrating that all sweeteners are equal (Fig. 22), quite far from the truth.
Everything published thus far in print, online, or TV suggests that the US health care system:

1. Designs, regulates, and implementation favors big business treatments, over simple prevention

2. Is too complex to effectively deliver equitable care to everyone, including and especially minorities who may have limited capacity to understand it, insufficient income to buy services, or misinformation that effectively hampers their decisions

3. May fail minorities disproportionately, because the system is not socially equitable, and instead favors the upper class's purchasing power

4. Functions without input from minorities, especially from subgroups with limited understanding of requirements, regulations, laws, allowances, exceptions, etc.

5. Engages in a responsiveness with big business to create laws and regulations that benefit those corporations

6. Favors expensive procedures over simple preventative interventions and imposes hardship and impediments to patients seeking straightforward treatments with known benefits

7. Prohibits and punishes practitioners and users of substance that are not approved through regulations delegated to agencies, even if benefits have been documented for centuries (particularly in Chinese medicine and Europe)

8. Supports the use of approved substances for treatment even when the full range of secondary, and particularly long-range effects are not fully known

9. Does not properly enforce the use of simple, non-convoluted language in adds pandering drugs for simple ailments in print, online, or TV and

10. Purports rhetoric equity and equality that is not supported by the disproportionate suffering of illness by minorities such as diabetes concentrated where the poor lives.

References


Haslam, Edward T. *Dr. Mary's monkey: how the unsolved murder of a doctor, a secret laboratory in New Orleans and cancer-causing monkey viruses are linked to Lee Harvey Oswald, the JFK assassination and emerging global epidemics* (Updated edition. ed.)

Hrabowski, Freeman. *A holding fast to dreams: empowering youth from the civil rights crusade to STEM achievement*.


I. General Information

The Journal of Healthcare, Science and the Humanities (JHSH) publishes a wide variety of articles intended to enrich and advance the knowledge of health and health care, science and the humanities, as well as the art and science of health care delivery and the health professions.

Program or project summaries/exemplars, formal case studies, or case scenarios are acceptable, but must be carefully constructed to avoid any subtle commercialization or politicization. Authors are free to submit academic manuscripts that present differing or alternative views to current issues and debates. The Editor will make final decisions regarding these issues after consultation with the members of the Journal Executive Leadership, including Intellectual Property Counsel if so required.

JHSH will not consider manuscripts that are being submitted or considered elsewhere simultaneously. If an author wishes to have a work rescinded from JHSH consideration for submission to another publication, the author must request in writing and be granted an official written notification regarding the same from the Editor or Senior Associate Editor.

Unless there is clear justification, and only with the written permission of the previous publisher, JHSH will not accept manuscripts published elsewhere, or that will be published prior to appearing in JHSH. Authors must inform the Editor of such matters at the time their manuscript is submitted; review by Intellectual Property Counsel may be required. Such matters must be acknowledged in the Author Note.

II. Representative Manuscript Categories

JHSH encourages authors to choose from a wide range of subject matter categories. Authors may explore various categories and possibilities with the Senior Associate Editor, who will subsequently discuss with the Editor. The Editor has responsibility for final decisions in this area. The following are representative categories.

a. Research papers, theoretical investigations.

b. Scholarly critiques and commentaries on various topics.

c. Formal case studies and program/project reports.

d. Reaction papers and editorials.

e. Book, film, media, law, education or other reviews.

f. Other academic or professional articles related to the JHSH interdisciplinary mission.

g. Creative work, including poetry and short fiction relevant to the JHSH mission.
III. Submission Review Processes

Submissions undergo a four-stage process of rigorous review, discernment, evaluation, and approval. The Editor may adapt these processes to meet specific circumstances.

Stage 1:

Authors submit full manuscripts or manuscript concept proposals to both the Editor and Senior Associate Editor. The Editor, Senior Associate Editor, and Associate Editors will conduct a preliminary assessment for relevance to the JHSH mission. The Senior Associate Editor will provide guidance to the corresponding author about shaping the manuscript for JHSH readers. All manuscripts, including all figures and graphics, must be formatted correctly and comply with JHSH Author Requirements before manuscripts will be allowed by the Editor to progress to Stage 2. Compliance with this requirement is mandatory. Exceptions will not be granted.

Stage 2:

After the Senior Associate Editor determines that all Stage 1 requirements are met and that all manuscript and graphics/figures formatting is in compliance, the Senior Associate Editor forwards the manuscript to the Chairs of the Academic Review Committee (ARC) for rigorous peer review. Also, at the time of Stage 2 submission, all authors must submit their completed Author Agreements and Copyright Release Forms. No article can be published unless this requirement is met by all authors. All journal peer reviewers have executed non-disclosure agreements and conflict of interest declarations to protect an author’s rights and academic property. Peer review routinely results in manuscript revision. The first author and the ARC Chairs work together to address matters stemming from peer review and to ensure that the manuscript is revised accordingly.

Stage 3:

After successful peer review and revision, the ARC Chairs send the revised manuscript to the Chairs of the Manuscript Editorial Committee (MEC) for rigorous editorial and formatting review, revision, and critique of actual content and language. This also includes careful review of all figures, graphics, and other related elements for compliance with requirements. The MEC also reviews, critiques and recommends minor formatting needs. The author and the MEC Chairs process and finalize the manuscript. When this process is completed, the MEC Chairs send the final manuscript back to the Senior Associate Editor as certified ready for final review.

Stage 4:

Upon receipt from the MEC Chairs, the Senior Associate Editor sends the final edition of the manuscript to the Journal Associate Editors for a final qualitative review. Any additional changes required are completed between the author and the Senior Associate Editor. Upon successful final qualitative review by the Associate Editors, the Senior Associate Editor sends the final edition to the Editor for final review and approval. If all items are in order, the Editor formally approves and accepts the manuscript for a future edition of JHSH. The Editor notifies the author of final acceptance.

Note: The Editor may make further determinations regarding requirements or revisions to manuscripts. In the event of circumstances, the Editor may disapprove a final edition.

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APA Style Web Resources: The URL links below provide additional information and assistance for APA style requirements.

http://owl.english.purdue.edu/owl/resource/560/01/
http://www.apastyle.org/elecref.html
http://www.psychwww.com/resource/apacrib.htm

Formatting Specifics:

In addition to meeting APA style requirements, articles must be organized according to the format below. All papers must be divided into appropriate, titled sections and subsections based on subject matter.

a. Introductory Material. Each manuscript must begin with the title, name of author(s) with current title(s) and institutional affiliation(s). With the exception of creative essays pre-approved by the Editor, manuscript titles shall be consistent with the scholarly and professional nature of the Journal. Informality, a casual tone and colloquialisms must be avoided. When using degrees after an author’s name, periods are omitted. (e.g., PhD, not Ph.D). Contact information for the corresponding author is to be included, either in the introductory material or as part of the Author Note. Authors are to provide complete, precise information for themselves and each co-author, to include street address, phone, fax and e-mail address (see example below):

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See Section VII below concerning requirements for designating authorship as opposed to contributors. Acknowledgments are placed in the Author Note.

c. Abstract. Immediately following the Author’s Note and without any page break, all articles will have an abstract of approximately 200 words. The abstract is a single, unindented paragraph of plain text without bullets or subsections. The abstract must use key information from the text to provide a clear, concise and unbiased summary. Review Articles or Creative Writing submissions do not have an abstract.

d. Keywords. Immediately following the abstract and without any page break, list at least three key words to facilitate electronic searches of the manuscript. The choice of key words will depend on the subject matter. Review Articles or Creative Writing submissions do not include key words.

e. Introduction. Immediately following the Keywords and without any page break, the text must begin with a section entitled “Introduction.” In the Introduction the author should preview what is about to be presented, and may chronicle the past history of the subject under discussion with appropriate use of references from the literature. Both the content and length of the introduction will vary according to subject matter. Review Articles and Creative Writing must include an introduction explaining the intent and providing important background to what follows.

f. Middle Sections. Based upon subject matter and methodology, the middle portion of the manuscript is to be divided into appropriate sections and subsections, each of which must be appropriately titled. See Section V for the formatting of section and subsection headings.

g. Conclusion. This section provides a concise summary of the materials previously presented, and points toward future or practical implications and/or implementation. Review Articles and Creative Writing should include a conclusion that points out the benefit of what has been presented to the reader and to the JHSH mission.

h. References. For those manuscripts requiring them, references will be listed on a separate page following the text. Accuracy is the responsibility of the author; references will not be validated in editorial review. The APA publication manual provides detail on the correct format for references. Review Articles do not require references, unless deemed by the Editor as essential. However, if useful Review Articles, Commentaries, Academic Reflections and other non-research presentations strictly speaking may offer Select Bibliographies or listings of works as For Further Reading.

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Manuscripts must be submitted (including tables and figures) in single spaced copy. Standard American or UK English usage and spelling are the norm, the latter for authors from UK English-speaking communities. Except for clearly stylistic conventions that can be reasonably justified in an academic and professional publication of this nature, authors are to avoid overly informal compositional style and language. Similarly, to maintain the highest level of academic quality, the use of the first person singular or plural is normally not accepted in English-speaking communities. Except for clearly stylistic conventions that can be reasonably translated between computing platforms or any content that cannot be shaped by desktop graphics technicians at the publishing house. For example, the use of references must not require editing or graphics personnel to obtain commercial notation software. Such editing must be able to be accomplished within MS Word. It is the responsibility of authors to require with this matter. Submission that do not comply will be returned until the matter is resolved.

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Bullets are not permitted within the text. Numbered or lettered lists are acceptable.

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All manuscripts are to be submitted to the Editor and the Senior Associate Editor as an e-mail attachment. All manuscripts must be submitted in MS Word format for MacOS and/or Windows (.doc or .docx format). Do not send manuscripts using the pdf or webarchive format. Such will be returned. See Section VI regarding graphics. Authors may wish to review examples of previously published articles as guides. These can be made available upon request.

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- Level 3: *Helvetica* 11pt Flush Left, Italicized, Uppercase and Lowercase Heading

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Chapter in an Edited Book:

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