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The Journal of Healthcare, Science and the Humanities

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FROM THE EDITOR’S DESK
Preface

Message from the Interim Editor

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The year 2015 and this edition of the Journal for Healthcare, Science and the Humanities (JHSH) mark another milestone in the legacy of the Journal, the National Center for Bioethics in Research and the Health Care (NBC), and Tuskegee University. Two thousand and fifteen marked 100 years since the death of Booker T. Washington, the founding principle and president of Tuskegee University (a.k.a. Tuskegee Institute). Tuskegee University honored his life and legacy by planning and implementing an event every month during 2015. With the exception of July and December, there were events in different parts of the country every month highlighting the multidimensional talents and accomplishments of Booker T. Washington. The series of events ranged from a session on the development of the movable school to educate rural children and adults throughout rural Alabama, who could not afford to travel to Tuskegee; his influence on Black people throughout the world, including Dr. W.E.B. Du Bois and Marcus Mosiah Garvey; his extraordinary fund raising ability and the founding of National Negro Health Week, in 1915. On April 17, 2015, the Centers for Disease Control and Prevention (CDC), the National Center for Bioethics in Research and Health Care and the Morehouse School of Medicine co-sponsored a 1-day symposium entitled, "From National Negro Health Week to National Minority Health Month.” The symposium focused on the health of African Americans and included scholarly papers; panel discussions and student poster presentations. Papers from the sessions, including the student poster presentation appeared in the December 2015 edition of the Journal for Healthcare, Science and the Humanities (Vol. V, Number 2)

Two thousand fifteen was also the 50th Anniversary of Bloody Sunday and the historic nonviolent march from Selma to Montgomery led by Dr. Martin Luther King Jr. and other civil rights leaders, protesting for African Americans’ right to vote in the Jim Crow South. Bioethics and public health ethics violations continue to challenge all segments of society, particularly vulnerable and susceptible populations, and people of good-will must address the violations to assure good science and social justice prevail. Overt bioethics violations are minimized by
Preface

institutional review boards (IRB) and other federal human subject research requirements. Public health efforts are reduced by adhering to principles and practices of community based participatory research. Expanding federal regulations to monitor human subject research and enhancing ethics courses taught in health professions schools are ongoing. Vigilance is needed nonetheless, to assure that bioethics and public health ethics violations are minimized. While not to belabor and or detail these ethics violations in both research and in health care delivery, suffice to say, the research community, the public health community and the general population, at large, must remain forever attentive to assure old mistakes are not repeated and new and avoidable ones never occur.

This issue to the Journal has an interesting array of articles including scholarly work which derived from the 2015 Public Health Ethics Intensive Course and the historic 1997 Presidential Apology Commemoration events at Tuskegee University. The theme of that forum was Assuring Ethics from Generation to Generation. Ralph Katz in his paper continues to raise the issue of mistrust and challenges the reader to reflect on the continued opportunity for the research community to build better relationships with populations they wish to engage through their research activities. Benedict Truman, in his response, agrees with Dr. Katz, on the one hand. Yet, on the other hand, he challenges the premise that underlies Dr. Katz’s comments. Kevin Williams, in his response to the presentation by Bailus Walker on the Affordable Care Act (ACA), reviews the literature on the law and stresses that ACA has reduced the uninsured in the U.S. But he warns that there remains much left to do.

Alton Pollard offers an insightful critique on #BlackLivesMatter; a victim of police brutality is Pollard’s age and Pollard ingeniously reflects on how oppression and hatred of “the other because of her or his skin color negatively impacts individual agency and communities. Malia Villegas and her colleagues discuss the critical role of assuring research ethics from generation to generation so that lessons learned among Tribal Nations will not be lost. Michelle Staples-Horne’s paper shared important information about health care for incarcerated youth in Georgia, which ironically is more available and accessible than for non-incarcerated youth.

Karen Bouye co-authors a critically thoughtful article with two colleagues, Karl. J. McCleary and Kevin Williams, who previously participated in one of CDC’s student pipeline programs. Two additional papers from Morehouse School of Medicine includes MPH students as co-authors and they are encompassed with the other papers. One, article lead by senior scholar, Stephanie Miles-Richardson and colleagues on mammographic screening, and the other lead by senior scholar Gemchu Gerbi and his colleagues on prostate-specific antigen testing provide interesting finding from the Behavioral Risk Factors Surveillance System.

The JHSH is committed to include the humanities, whenever possible. Two articles, one by Rhonda Collier on Afro-Brazilian Female Rappers and the other on the relevance of Negro spirituals, by Archibald Laud-Hammond, provide an interesting contrast of music by afrodescendant people. Consistent with the importance of including the humanities in the JHSH, Rhonda Collier's article from Brazil on Afro-Brazilian Female Rappers and Archibald Laud-Hammond's discussion on Negro spirituals provide intriguing examples on the depth, breath and value of music as an important discipline in the humanities. Some suggest that music is a universal language that is yet to be fully explored. Lastly, Clyde Robertson reviews the book entitled, Bus Ride to Justice: The Life and Work of Fred Gray. Attorney Gray was the lead attorney in Pollard vs. United States of America, who represented the 623 men who were misled into participating in the infamous U.S. Public Health Service Syphilis Study at Tuskegee and Macon County, Alabama. Dr. Robertson does an extraordinary job in his review of the life’s work of this legal giant. In summary, the JHSH continues to synergize the contributions of a transdisciplinary group of scholars, with expectations that combining the strengths of their disciplines will yield new ideas, new insight and new opportunities to improve the human condition and quality of life for all people. Please enjoy this edition!
Was the Development of the Mistrust-In-Research (MIR) Field of Study Yet Another ‘Legacy of the USPHS Syphilis Study at Tuskegee’?

A Case Study in Passing Ethics Research from ‘Generation to Generation’

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A 2015 PHEIC Symposium Keynote Address by Ralph V. Katz

Introduction
The theme of this year’s Public Health Ethics Intensive Course (PHEIC) Symposium at the Annual Commemorative Event at Tuskegee University honoring the families of the infamous 40-year long United States Public Health Service (USPHS) Syphilis Study at Tuskegee (1932-72) is ‘Ensuring Ethics Generation to Generation’. In keeping with that theme, this paper is presented as a case-study that addresses that theme in two ways. First, its very presentation here today ensures that the ethics inquiry into the legacy of the USPHS Syphilis Study at Tuskegee continues into the 21st century, for the younger generations ‘to hear’. Second, the project that was conducted over the past three years by the very nature of the composition of the research team (with its team members ranging from 70 year olds down to 20 year olds) ensures ‘the passing of
the baton' on this line of ethics research between generations, i.e., from pre-Baby Boomers to the current Millennium-X generation.

Further, it is hoped that this Keynote presentation will trigger a vigorous discussion in the panel that follows, both on the interpretations of these data as presented and on the ever-valuable question: "Where to from here?"

The overall goal of this systematic review of the Mistrust-In-Research (MIR) literature was to explore whether the USPHS Syphilis Study at Tuskegee—frequently referred to as the Tuskegee Syphilis Study (TSS)—may plausibly have been 'the trigger event' that led to the development of Mistrust-In-Research as a research-based field of study. The primary outcome objective of this project was to create a simple graph that would show the number of MIR original research articles published year-by-year over a period of 110 years from 1900 - 2011.

Conceptually, this was envisioned as being comparable to an epidemiologist creating a classic epidemic outbreak curve to track the specifics of that epidemic from initiation by identifying the index case (i.e., the first case) through its peak intensity in the community, right up to the end of the epidemic, i.e., the last case diagnosed. Specifically, such a graphic of an epidemic outbreak curve would show the number of new cases of a given disease on a day-by-day to allow the epidemiologist to understand—and hopefully use that understanding to control—the epidemic by mapping out the initiation of the disease outbreak, the daily progression of that disease outbreak, and follow it right up to its cessation.

The lead author of this research team (not surprisingly then, an epidemiologist) envisioned adapting this well-known tool, used successfully for over 150 years by epidemiologists, to graphically illustrate the timing of the 'outbreak' of MIR original research articles on a year-by-year basis from 1900 through 2011. The final step envisioned would consist of looking at that histogram showing the number of original research MIR articles published year-by-year and determining where it intersected with the trigger event 'of interest', i.e., the 1972 news media disclosure of the infamous USPHS Syphilis Study at Tuskegee.

The initial research hypothesis then of this study was whether the media disclosure of the USPHS Syphilis Study in 1972 was 'the trigger event' that led to the development of Mistrust-In-Research as an original research field. Stated succinctly in layman's terms: 'Was the development of the Mistrust-In-Research line of inquiry as a research field a 'legacy' of the Tuskegee Syphilis Study?'

Brief Background on the ‘Legacy of the USPHS Syphilis Study at Tuskegee’

The USPHS Syphilis Study at Tuskegee, aka the Tuskegee Syphilis Study began as a planned six-nine month cross-sectional study to document the range of syphilis-related pathology in 399 Black male subjects who had syphilis and 201 Black non-syphilitic male control subjects in Macon County, Alabama. (Jones, 1981) It seamlessly evolved into a long-term prospective cohort study with the goal of documenting the progression of untreated syphilis in Black males. The study continued for 40 years until it was abruptly ended by the USPHS in 1972 due to the public shock and uproar which immediately followed major newspaper disclosure of the unethical and racist nature of the study. (New York Times, 1972; The Anniston Star, 1972; The Titusville Herald, 1972; Albuquerque Journal, 1972) In 1981 James Jones, a Professor of History at the University of Houston, published the book Bad Blood, to this day considered the definitive history of this infamous study. (Reverby, 2000; Reverby 2009)

In 1994 at a bioethics conference at the University of Virginia entitled: "The Legacy of the Tuskegee Syphilis Study: Doing Bad in the Name of Good", medical historians, medical sociologists and bioethicists at that conference all spoke of the ‘known and widely recognized legacy’ of the Tuskegee Syphilis Study, namely that African-Americans would not participate in biomedical studies due to their awareness of this infamous study in their talks that day… yet they gave no research-based citations or references to support that belief. (University of Virginia Bioethics Conference, 1994) Subsequently, a comprehensive literature search confirmed that lack of research evidence. Thus, despite the fact that there had been no direct research conducted into this widely accepted hypothesized ‘legacy’ at that time, that stated ‘legacy of the Tuskegee Syphilis Study’ was the prevailing belief over the past two decades ever since that infamous study’s disclosure and termination in 1972. As one researcher subsequently characterized that belief, it apparently was a belief "...known in their guts, not in their heads". (Katz, Kegeles, Green, Kressin, James & Claudio, 2003)

However, subsequent investigative field research in the following period of 1995-2010 into that ‘so-called and widely accepted’ legacy—in a wide range of studies across the U.S.—failed, overall, to document any difference between Blacks and Whites on self-reported willingness to participate in biomedical studies despite detecting a greater wariness and concern among Blacks about such participation. (Freimuth, Quinn, Thomas, Cole, Zook & Duncan 2001; Fouad, Corbie-Smith, Curb. Howard, Mouton, Simon,...Young R 2004; Wendler, Kingston, Madans, Van Wye. Christ-Schmidt, Pratt,...Emmanuel 2006; Katz, Kegeles, Kressin, Green, Wang, James,...Claudio, C., 2006; Katz, Green, Kressin, Claudio, Wang & Russell 2007; Katz, Green, Kressin, James, Wang, Claudio, & Russell 2008)

In light of those recent consistent research findings not supporting that ‘so-called legacy of the Tuskegee Syphilis Study; a book was published in 2011 in which leading U.S. authorities across a variety of disciplines (e.g., history, anthropology, sociology, medicine, and health disparities research) wrote essays postulating what each of them believed to be ‘the true legacy of the Tuskegee Syphilis Study’. (Katz & Warren, 2011) Most recently, our Tuskegee Legacy Project (TLP) research team undertook a comprehensive and systematic review of the Mistrust-In-Research (MIR) literature to explore whether the USPHS Syphilis Study at Tuskegee may plausibly have been ‘the trigger event’ that led to the development of Mistrust-In-Research as a research-based field of study. The results of that latest study by our current TLP research team is presented in this paper.

Methods

Given that the USPHS Syphilis Study at Tuskegee began in 1932, ran for 40 years and was ended in 1972, when it was disclosed widely in the U.S. media (i.e., newspapers and TV), the decision was made to conduct the systematic literature search starting with year 1900 (to be sure to include 3 decades before the start of the Tuskegee Syphilis Study) and ending with 2011, the year in which this project was begun, a total literature search period of 111 years, as shown
in Table 1. This systematic literature search was conducted by a biomedical librarian (research team member R McGowan). Table 1 also shows the details of the search strategy and specific terminology used within the three databases that were used to identify relevant MIR original research articles, i.e., Pubmed, Embase, and Embase Classic. This literature search using the above named three databases initially identified a total of 1,016 abstracts which was then reduced to a final total of 710 identified relevant and separate abstracts when duplicate abstracts were removed.

The six research team members, who—collectively—read and evaluated each abstract and its full published article both to determine relevance to our project and to abstract specific information are hereafter referred to as ‘abstractors’ (A Congiusta, TC Tien, MC Chetcuti, JY Lee, BD Casagli and BA Dearing). The initially identified 710 abstracts were subjected to a seven-step process in order to identify only those MIR studies which resulted from published Mistrust-In-Research original research papers, i.e., those published papers which reported original research findings. The original research data could be either quantitative or qualitative data, but any papers which were identified as ‘opinion’ or ‘commentary’ papers without any original data were classified as being not relevant to the purpose of our study. This was done as our goal was to identify only those published reports that constituted the literature of ‘investigative studies’ within the published Mistrust-In-Research literature. That is, we were only interested in that subset of MIR published papers that reported the findings of active data-collection studies...to determine whether the TSS had triggered those lines of data-based inquiry.

The seven-step review process consisted of:

1) all six abstractors first being calibrated in the use of the MIR Abstract Categorization (MAC) form which was used as the initial screening step on the originally identified 710 abstracts;

2) an independent reading and completion of the MAC form by 2 abstractors for all 710 identified published abstracts;

3) resolution of any disagreements between 2 abstractors on a completed MAC form for a given abstract was via a discussion between them

4) obtaining of e-copies of all 279 MIR published articles as identified as likely relevant by the MAC screening step;

5) all six abstractors being calibrated in the use of the Relevant Article Abstraction Categorization (RAAC) form;

6) an independent reading and completion of a RAAC form by two abstractors for each of the 279 MAC-screened published articles; and

7) resolution of any disagreements between 2 abstractors on a completed RAAC form for any given abstract via a discussion between the 2 abstractors and the lead investigator (RV Katz).

This seven-step process resulted in a grand combined total of 1,978 completed categorization forms as based upon 1,420 abstract readings and 558 article readings. These activities were conducted over a two-year period, 2012 – 2014, in order to accommodate the abstractors’ schedules as four of the six abstractors were full-time enrolled dental students.

The MAC form (see Table 2) as used to categorize the originally identified published abstracts consisted of five items, three of which were straightforward data to be abstracted and recorded (the Abstract ID #, the year of publication, and the journal in which it was published)
Articles

and two of which required the Abstractor to make judgments: item #4 asked: Is this a Research Article, and item #5 asked: Is this article of interest for our MIR Project? The eligibility criteria used in making the judgments for items #4 and #5 were:

1) If the answer to either item #4 or item #5 indicated it clearly was not a research article (i.e., either was a “2” on item #4 OR a ‘4’ to item #5, we terminated the MAC form and the corresponding article would NOT have moved on to RAAC analysis. The ‘rule of thumb’ for both the original scoring AND the resolution of discrepancies was: err on the side of being ‘inclusive’ (vs ‘exclusive’), i.e., if in doubt, move it forward to next level of review.

2) Additionally, as part of the MAC analysis, we terminated abstracts that were only from meetings (e.g., APHA, SER, IADR, etc.) and never led to a published article in a scholarly journal, with the result that these abstracts would NOT move on to the next step in the process, i.e., the RAAC analysis of the published article.

The RAAC form was constructed to abstract 16 items of information from each of the 278 published articles that had been categorized as ‘likely relevant original MIR research articles’ via the screening by the MAC form step of this review process. Table 3 shows the first 5 items on the RAAC form, which are the only items on this form relevant to this paper. Those 5 items, as can be seen, are exact duplicate questions as taken from the MAC form. By completing these first 5 items of the RAAC form the Abstractor was performing a verification check on the ‘relevance’ of that individual study as regards its being, in fact, an original research article, scholarly journal, with the result that these abstracts would NOT move on to the next step in the process, i.e., the RAAC analysis of the published article.

Results

The initial comprehensive literature search covering the 111 year time period from 1900 – 2011 identified a total of 1,016 abstracts which was then reduced to a final total of 710 identified relevant and separate abstracts when duplicate abstracts were removed. The seven-step review process on these 710 abstracts yielded 279 ‘likely relevant’ original MIR research abstracts after the MAC screening step. The final review steps associated with the RAAC review of these 279 published articles yielded a final total of 189 MIR original research articles which formed the database for analysis in this project.

Secondly, the histogram clearly shows a steady but slow increase in the number of published MIR abstracts from 1992 through 2001, with an acceleration in the number of published MIR abstracts per year observed from 2002 – 2006, after which the number of abstracts per year appears to have reached a plateau. [N.B., The data for 2011 is only data for the first nine months of 2011, which explains the observed dip in final year].

Figure 1 is a histogram showing the distribution of the year-by-year number of the 710 abstracts that were subjected to the MAC review screening step, i.e., pre-MAC review. First, it should be noted that the first of these identified abstracts appeared in the literature in 1992. Secondly, the histogram clearly shows a steady but slow increase in the number of published MIR abstracts from 1992 through 2001, with an acceleration in the number of published MIR abstracts per year observed from 2002 – 2006, after which the number of abstracts per year appears to have reached a plateau. [N.B., The data for 2011 is only data for the first nine months of 2011, which explains the observed dip in final year].

Figure 3. Number of published Mistrust in Research (MIR) articles over a 20-year period at three levels of the literature review process: Initially-identified, post-MAC review and post-RAAC review.
The histogram shown in Figure 2 adds the data obtained from the MAC review step for the 279 abstracts that were screened as positive for 'likely being an original MIR research study' to the already existing plotted line for the 710 pre-MAC review abstracts originally identified in the comprehensive literature search. The same trend patterns over time are seen for the post-MAC screening review abstracts, albeit with a markedly reduced number of abstracts in any given year compared to the pre-MAC review data. For the latter plateaued time period of 2002-2011, the number of plotted 'likely original research MIR abstracts' per year ranges between 20-28 MIR original research articles per year, or about 75% of what was observed in the articles on a year-by-year basis with the peak plateaued years of 2006 – 2011 showing a range graphed for the published MIR original research articles as was observed for the MIR abstracts. Thus, the same time general trend patterns are observed over the twenty years the data for 2011 is only data for the first nine months of 2011, which explains the observed MIR original research articles appears to reach a plateau of ~20 articles per year. [N.B., Again, increasing to ~10 in each of these years. Finally, from 2006 – 2011, the number of published MIR original research articles appears to reach a plateau of ~20 articles per year. [N.B., Again, the data for 2011 is only data for the first nine months of 2011, which explains the observed dip in final year]. Thus, the same time general trend patterns are observed over the twenty years graphed for the published MIR original research articles as was observed for the MIR abstracts.

Figure 3 presents the full display of all the relevant data by adding the findings of the year-by-year time-trend data for articles that were confirmed as original research MIR studies by the RAAC review of the published articles. The histogram shown in Fig 3 clearly shows a steady but slow increase in the number of published MIR original research articles from 1994 through 2002, increasing from 1 article per year to 6 articles per year in 2002. From 2003 – 2005 there is a noted increase in the number of published MIR original research articles per year observed, increasing to ~10 in each of these years. Finally, from 2006 – 2011, the number of published MIR original research articles appears to reach a plateau of ~20 articles per year. [N.B., Again, the data for 2011 is only data for the first nine months of 2011, which explains the observed dip in final year]. Thus, the same time general trend patterns are observed over the twenty years graphed for the published MIR original research articles as was observed for the MIR abstracts.

However, there was a notably lessened reduction in number of positively-identified articles on a year-by-year basis with the peak plateaued years of 2006 – 2011 showing a range between 20-28 MIR original research articles per year, or about 75% of what was observed in the post-MAC plotted MIR abstracts for these same years.

Discussion

The full dataset, as presented in Fig 3, reveals the following facts. First, that the earliest original research MIR article was published in 1994, with no detected original research MIR studies prior to that date, based on a literature search that went back to 1900. Second, once initiated in 1994 the year-by-year number of MIR original research published articles shows a steady increase per year until 2006 when it hits its plateau of about 20 articles per year which is maintained through the end of the observation period, i.e., 2011.

The initial question, or hypothesis, of the research team was whether the news media disclosure and immediate public reaction of shock and anger was the likely trigger event that led to the development of the MIR (Mistrust-in-Research) research based field of study. For the evidence to seen as supporting that hypothesis, two criteria would have to have been met by the data in the created histogram. First, the earliest MIR original research articles would have to occur after 1972, the year in which the news media disclosure occurred, and after which the adjective 'infamous' would be forever more be a prefixed to that study's name. Second, the histogram should show the occurrence of those MIR original research articles after an expected lag-time of some 8-10 years, i.e., in the early to mid 1980's. This expected lag-time was based on the initial silent period typically encountered in the literature between the conceiving of the idea of a field project and the completion of the first wave of studies conducted through the final act of dissemination of findings, i.e., published articles. Typically, that cycle would take 8-10 years: 1-3 years to write grants and obtain funding, 3-4 more years to conduct the study, 1 year to analyze the data and write manuscripts, and 1-2 years for the articles to appear as published articles. So, one would expect the initial appearance of MIR original research based articles to appear in the 1980-83 time period if the original hypothesis was to be supported by the year-by-year publication data in the histogram.

However, as can be plainly seen in the histogram in Fig 3, this is not what the year-by-year publication data showed. While the first criteria was met by the observed data (i.e., the first MIR original research article did indeed appear after the 1972 media disclosure of the USPH Syphilis Study at Tuskegee), the observed lag-time was twice as long as had been anticipated, i.e., the first MIR original research article appeared in 1992, not the anticipated 1982 appearance. This left the research team in a quandary as they tussled with alternative explanations for this 'two times longer than anticipated' observed lag-time period.

Then serendipity—as seemingly is so often the case—intervened 'to show the way'. While the research team was 'quandering' (i.e., searching for a logical explanation) over the 'misfit' of the data to their original hypothesis, the lead author—by happenstance—had an epiphany during an unrelated, routine email correspondence. In a seemingly unrelated event, the author of a chapter in a recently published book that had been edited by the lead author of this project had inquired if, by any chance, the lead author still had an electronic version of that man's book chapter as he had either misplaced or accidentally erased his own copy. It was as the lead author of this paper was typing out his 'good news', albeit mundane, response (for he did indeed have that e-copy to send), that the epiphany exploded in his brain. As it would be, the chapter author making the inquiry was none other than James Jones, the historian who had written Bad Blood, the definitive history of the Tuskegee Syphilis Study...which apparently led to synapses firing in the lead author's head connecting the dots between our research team's present quandary and Bad Blood with its publication year of 1981. And, in that mid-mundane, email-writing moment….a second hypothesis was 'born and borne'.

The trigger event to spark the academic community of scholars into MIR research action was, perhaps, not the ephemeral 1972 news media event. Rather it was those academic scholars’ deliberative reading of Bad Blood, the definitive history of the Tuskegee Syphilis Study, published in 1981, that left a lasting impression, leading them to ponder the myriad, yet unknown issues that would result from such a shocking misuse and abuse of U.S. citizens as research subjects, at the hands of their own government no less.

This second proposed hypothesis (namely that the trigger event for the development of the MIR research field of study was the publication in 1981 of James Jones’ Bad Blood) did 'fit the lag-time of the observed data'. This second proposed hypothesis fully meet the second of the established two criteria as set at the beginning of this MIR project three years ago, whereas the original hypothesis does not. Specifically the originally postulated 8-10 year lag-time period criteria is met by this second proposed trigger event, i.e., the publication of Bad Blood in 1981.
Conclusion

To be both clear and sure, the strongest statement—at this time, in this line of investigation into the trigger event for the MIR research field—that can be made based on the data in Fig 3 is that the publication of James Jones’ book Bad Blood plausibly was the trigger event for the development of the MIR field of research. Stated another way, the data in Fig 3 are supportive of this second (and quite serendipitously discovered) hypothesis, namely that the 1981 publication of James Jones’ Bad Blood was the trigger event for the development of the Mistrust-In-Research (MIR) field of research. Not that serendipity would have played a significant role in developing a scientific line of inquiry for the first time in the annals of the history of science...and hence the ‘serendipitous epiphany’ during the routine email correspondence is not problematic in the least.

This story is likely more just begun than ‘fully explained’ at this stage of inquiry into the broad relationship between the USPHS Syphilis Study at Tuskegee and the MIR line of investigation, much less into the specific search for the trigger event(s) for the development of the Mistrust-In-Research (MIR) field of research.

Thus the search for the full ‘legacy’ of the USPHS Syphilis Study continues, and here is actively passed from generation-to-generation. This specific line of MIR inquiry then joins other identified lines of inquiry related to the Mistrust-In-Research field of study to pave the way to the future. (Cohen & Arieli T, 2011; James, West, and Madrid, 2013; Yeager, Purdie-Vaughns, Garcia, Apfel, Brzustoski, Master,...Cohen. 2014) Nevertheless, the data in this study moves the MIR line of inquiry forward, perhaps having discovered (uncovered?) yet another heretofore unknown ‘legacy’ of the USPHS Syphilis Study at Tuskegee: that the publishing of James Jones’ definitive history of that infamous study in 1981, Bad Blood, was a trigger for the development of the Mistrust-In-Research (MIR) field of research.

References


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**Table 1.** Search strategy and terminology for the initial comprehensive literature search for original research articles in the field of Mistrust-In-Research (MIR) for the years 1900 – 2011, a 110 year period.

**Pubmed search: 1900 to 2011, week 48, resulted in 691 abstracts:**

**Search Strategy:**

\[(\text{mistrust [All Fields]} \text{ OR “trust”[MeSH Terms]} \text{ OR “trust”[All Fields]} \text{ OR conspiracy [All Fields]} \text{ OR “fear”[MeSH Terms]} \text{ OR “fear”[All Fields]})\]

\[\text{AND}\]

\[(((\text{biomedical[All Fields]} \text{ OR medical[All Fields]})) \text{ AND (“studies”[All Fields]} \text{ OR “research”[MeSH Terms]} \text{ OR “research”[All Fields]})) \text{ OR “Biomedical Research”[Mesh]} \text{ OR “Research”[Mesh]})\]

\[\text{AND}\]

\[((\text{“african americans”[MeSH Terms]} \text{ OR (“african”[All Fields]} \text{ AND “americans”[All Fields]}) \text{ OR “african americans”[All Fields]} \text{ OR “african american”[All Fields]} \text{ OR “minority groups”[MeSH Terms]} \text{ OR (“minority”[All Fields]} \text{ AND “groups”[All Fields]}) \text{ OR “minority groups”[All Fields]} \text{ OR “minorities”[All Fields]} \text{ OR “minority”[All Fields]})\]

\[\text{AND}\]

\[((“1900/01/01”[PDat] : “2012/01/01”[PDat]))\]

Embase Classic + Embase; 1947 to 2011 Week 48, resulted in 325 abstracts:

**Search Strategy:**

\[\text{1 (mistrust or trust or fear or conspiracy).mp. or exp trust/}

\[(\text{african americans or african american or minorities or minority).mp. or exp}}\]

\[\text{2 exp African American/ or exp minority group/}

\[(\text{biomedical research or medical research or medical studies or}}\]

\[\text{3 biomedical studies).mp. or exp medical research/ or exp research/}

\[\text{4 1 and 2 and 3}}\]

\[691 + 325 = 1016 \text{ total abstracts, which were reduced to 710 identified abstracts when duplicates were removed}\]
Table 2. The Mistrust Abstract Categorization (MAC) form used as a screening form to categorize the 710 initially identified Mistrust-In-Research (MIR) abstracts into those that were, or were not, of ‘of interest’ to our MIR Project.

The Mistrust Abstract Categorization (MAC) Form

1) Abstract #:

2) Year of Publication:

3) Journal:

4) Is it a Research Article: ______ (enter one # below choices. If ‘No’, enter ‘2’ and TERMINATE/end the MAC)
   1. Yes, clearly a Research article which collected original data on individual subjects
   2. No, clearly a non-research article (only author opinion)
   3. Maybe Yes, but a ‘research study’ only as ‘case-report’ with community-level data only
   4. Maybe, not certain if it is a Research article (questionable)

5) ‘Is Article of Interest for our MIR Project?” ______ (enter one # below choices)
   1. Yes, on Mistrust in Research (i.e., on ‘patient – doctor/provider relationship’ WITHIN a research study) ONLY
   2. Yes, on Mistrust in Health Care (i.e., on non-research ‘patient – doctor/provider relationship’) ONLY
   3. Yes, BOTH #1 and #2
   4. No, definitely does NOT address Mistrust in either ‘research study’ nor in ‘health care’ situation
   5. Clues exist, but uncertain (i.e., needs collaborative reviewers)
   8. UNKNOWN

Table 3. The Relevant Article Abstraction Categorization (RAAC) form used as a check to verify that 279 abstracts screened as ‘likely original research articles’ via the MAC screening step were, indeed, confirmed as original research when the full articles were read.

The RAAC* Form for MIR Project (* = Relevant Article Abstraction Categorization)

1) Abstract #:

2) Year of Publication:

3) Journal:

1* re-score it on MAC criteria….this time using the full article:

4) Is it a Research Article: (bold one choice, if ‘No’, bold choice 2 and TERMINATE/end the RAAC)
   1. Yes, clearly a Research article which collected original data on individual subjects
   2. No, clearly a non-research article (only author opinion)
   3. Maybe Yes, but a ‘research study’ only as ‘case-report’ with community-level data only, not survey of individuals
   4. Maybe, not certain if it is a Research article (questionable)

5) ‘Is Article of Interest for our MIR Project?” (bold one choice below)
   1. Yes, on Mistrust in Research (i.e., on ‘patient – provider relationship’ WITHIN a research study) ONLY
   2. Yes, on Mistrust in Health Care (i.e., on non-research ‘patient – doctor/provider relationship’) ONLY
   3. Yes, BOTH #1 and #2
   4. No, definitely does NOT address Mistrust in either ‘research study’ nor in ‘health care’ situation
   5. Clues exist, but uncertain (i.e., needs collaborative reviewers)
   8. UNKNOWN

then…….IF (and only ‘if’): q#4 = 1  AND  q#5 = 1, 2, 3 AND then abstract the following ‘data/info’ from the full article: [otherwise TERMINATE filling out this form here!!]

…..followed by items #6-16 (which are not relevant to this paper)
Response to the Keynote Address by Ralph V. Katz Regarding the Publication Event that Launched the Mistrust-In-Research Field of Ethics Study, 1900–2011

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Author Note
This article was prepared from the author’s presentation at the March 2015 Public Health Ethics Intensive Course and is based on his response to the keynote address at that event by Ralph V. Katz, DMD, MPH, PhD, New York University College of Dentistry. The author thanks Ms. Cheryll (Kay) Smith for technical writing and copy-editing assistance in preparing the manuscript for publication. The findings and conclusions in this report are those of the author and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Abstract
At the 2015 Public Health Ethics Intensive Course at Tuskegee University, Ralph Katz combined methods from epidemiology, research synthesis, history, theology, and philosophy to describe a field of study he terms “Mistrust-In-Research” (MIR). Dr. Katz posits that MIR literature will reveal the publication that launched the field, thus leading to knowing more about the Tuskegee Syphilis Study (TSS) legacy. By transmitting that research from one generation to the next, the TSS legacy will continue. Dr. Katz assumed that MIR research is like a common source disease outbreak, and the lag from the cause to publication of the first MIR article was 8–10 years. He concludes that the first complete account of the TSS in James Jones’ Bad Blood: The Tuskegee Syphilis Experiment in 1981 launched the MIR field. I agree with Dr. Katz that a multigenerational research collaboration will transmit the TSS legacy to future generations and that continuation will ensure that the positive influence of that legacy continues and perhaps even increases. However, I recommend that Dr. Katz’s team carefully examine the MIR studies to identify the publications that motivated them. Those publications encapsulate the ideas that launched the search for explanations of the mistrust in research field.

Keywords: biomedical ethics, Tuskegee Syphilis Study, intergenerational relations, trust

Introduction
In his keynote address at the March 2015 annual Public Health Ethics Intensive Course at Tuskegee University, “Was the Development of the Mistrust-In-Research (MIR) Field of Study Yet Another ‘Legacy of the USPHS Syphilis Study at Tuskegee’?” Ralph Katz combined methods from five different disciplines to tell a creative story about the birth and development of a field of study he has named “Mistrust-In-Research” (MIR) (Katz, 2015). He borrowed an epidemic curve (from epidemiology), a systematic review of the literature (from research synthesis), and a historical analysis (from history) to tell his creation story (from theology) of a field of ethics research (from the domain of philosophy). What follows is a summary of the message in Dr. Katz’s keynote address and a description of the multiple generations who comprise today’s society and Dr. Katz’s research team. I will examine the evidence Dr. Katz used to support his conclusion regarding the event that inspired MIR studies by describing how to interpret a typical epidemic curve and then comparing that interpretation with Dr. Katz’s epidemic curve. Finally, I will assess the adequacy of his evidence and end with my view of Dr. Katz’s message and its implications for the legacy of the Tuskegee Syphilis Study (TSS) for future generations.

Dr. Katz’s message can be summarized as follows: (1) If we review the MIR literature, we will find the publication that inspired the field; (2) if we know the event that launched the MIR field of research, we will know more about the TSS legacy; (3) the research team is multigenerational; therefore, the TSS legacy is being transmitted from generation to generation; and (4) if a new generation continues this research, the TSS legacy will live on.

U.S. Generations by Birth Cohort and Age in 2015
To understand Dr. Katz’s hypothesis, we must first examine how different generations living today are defined. The Silent Generation includes persons born before 1946; those persons are now 70 years old or older and were born either before or during World War II. They are called the Silent Generation because, having lived during the Great Depression and a devastating world war, both of which required considerable daily sacrifices, they were taught to endure the hardships in life without complaint (Taylor & The Pew Research Center, 2014). Persons born during 1946–1964, the years immediately following World War II and the Korean War, are the Baby Boomers. They are now 51–69 years old and were so named because of the sharp increase in births shortly after the soldiers of both conflicts returned home (Taylor & The Pew Research Center, 2014). That generation is now preparing to retire, has recently retired, or is choosing to work longer than typical retirement age. Because of the pressures Baby Boomers place on the nation’s social, healthcare, and economic infrastructures, they have a strong influence on U.S. politics (Manual, 2015a). Generation X refers to persons born during 1965–1980 and who are now 35–50 years old. Gen Xers, as they are often called, have been portrayed by the media as slackers, but Gen Xers have been instrumental in the dramatic adoption of personal computers, the Internet, cellular telephones, and mobile devices that define today’s culture (Manual, 2015b). The Millennials, also known as Generation Y, are those persons born during 1980–1997 and who are now 18–34 years old. They are either still attaining their education or are in the early stages of their careers, and many have been deeply affected by the worldwide economic crisis of the past decade (Taylor & The Pew Research Center, 2014). The Next Generation was born after 1997, and they are now only 1–17 years old. The societal challenges they will face are yet unknown. In Dr. Katz’s introduction, he
Interpreting an Epidemic Curve

The second element of Dr. Katz’s message that we must understand is how to interpret an epidemic curve. Figure 1 is a typical epidemic curve (often referred to by epidemiologists as an epi curve) that illustrates an outbreak of gastroenteritis cases associated with eating raw or undercooked clams (Truman et al., 1987).


**Figure 1.** Typical epidemic curve illustrating the number of cases of gastroenteritis associated with eating clams, by 12-hour interval of illness onset, Rochester, New York, November 1983.

The epi curve indicates that a total of 84 cases of viral gastroenteritis occurred among firemen and sporting event ushers who had attended two separate clambakes on November 5, 1983, in Rochester, New York. The shape of the curve indicated a common or point-source outbreak, and on the basis of the patients’ symptoms, the investigators suspected foodborne norovirus. From the known incubation period of 1–2 days for norovirus, they calculated November 5 or 6 as the most likely exposure period by subtracting the shortest incubation period (1 day) from the date of illness onset for the first patient (November 6), which equals the earliest possible exposure date, November 5. They then subtracted the longest incubation period (2 days) from the date of illness onset for the last patient (November 8), which equals the latest possible exposure date, November 6. By using the epi curve, the investigating epidemiologists were able to interview the affected patients to determine what foods or beverages the majority of patients consumed in common on November 5 or 6. For that outbreak, the norovirus infection vehicle was conclusively identified as the clams the patients had eaten at the clambakes on November 5 (Truman et al., 1987).

Interpreting Dr. Katz’s Epidemic Curve

Dr. Katz assumed that (1) the MIR research field was like a common source disease outbreak, and (2) the lag period from the common source (Dr. Katz terms it the trigger event) to publication of the first MIR article (i.e., publication of the abstract) was 8–10 years (the time required for obtaining funding, completing the study, and publishing the results) (Figure 2).

He plotted an epidemic curve of MIR articles (abstracts) published during 1994–2011 and calculated the most likely year of the causal event by subtracting the shortest lag period (8 years) from the year the article was published (1994), which equals the earliest year of the causal event (1986). He then subtracted the longest lag period (10 years) from the year of the last article (2011) of his study period, which equals the latest year of the causal event (2001). Thus, the most likely year of occurrence of the causal event was sometime during 1986–2001.

Adapted from: Katz, R. V. (2015, March). Was the development of the mistrust-in-research (MIR) field of study yet another “legacy of the USPHS Syphilis Study at Tuskegee”? A case study in passing ethics research from “generation to generation.” Keynote address presented at the Annual Public Health Ethics Intensive Course, Tuskegee University, Tuskegee, Alabama.

Note: The events in 1972, 1981, and 1993 have been added by this author for context.

**Figure 2.** Number of Mistrust-In-Research articles published each year, 1994 through the first six months of 2011.
Dr. Katz’s Causal Event of MIR Literature

Before the study, Dr. Katz expected that the data would indicate that the most likely causal event occurred in 1972, the year that the public first became aware of the TSS from media reports. However, the epidemic curve did not support that conclusion because the data did not fit the expected 8–10-year lag. After his study, Dr. Katz concluded that the epidemic curve pointed to the causal event occurring in 1981 because those data did fit the 8–10-year lag. The significant event of 1981 was publication of the first complete account of the TSS, Bad Blood: The Tuskegee Syphilis Experiment by historian James H. Jones (Jones, 1981).

Does the Evidence Support Dr. Katz’s Conclusions?

My answer is a qualified somewhat, but not entirely! The scientific explanation of my answer is as follows: Knowing when the hypothesized causal event occurred does not prove that a particular event was causal. My interpretation of Dr. Katz’s epidemic curve locates the causal event during 1986–2001, which is 5–10 years after 1981. Any event or series of events that occurred during that period might have been one or more causal events or inspiration (i.e., justification) for MIR studies published during 1994–2011.

Publication of the new and expanded edition of Bad Blood: The Tuskegee Syphilis Experiment in 1993 or anything else that occurred during 1986–2001 might have inspired the MIR studies published during 1996–2011 (Jones, 1993). In his preface to the expanded edition, Jones noted that the 1981 edition of Bad Blood and the “story of AIDS” both unfolded in the media in 1981, and certain black persons have used the TSS to support a conspiracy theory that “AIDS is a form of racial genocide employed by whites to exterminate blacks” (Jones, 1993:ix-x).

MIR authors have provided literature citations other than Bad Blood in documenting the origins of the ideas and knowledge gaps that inspired their studies. For example, in their 1988 MIR study of “The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community,” Stephen B. Thomas and Sandra Crouse Quinn cited the following additional sources (Thomas & Quinn, 1991):


Content analysis of such citations can provide more persuasive evidence of the historical causes of the MIR field than is available in Dr. Katz’s epidemic curve.

Conclusion

In conclusion, I contend that the publication or other events that launched the MIR field still remain hidden in plain view in citations in Dr. Katz’s data that were not presented in his keynote address. I agree with Dr. Katz that continuing the multigenerational research collaboration will transmit the TSS legacy from generation to generation (“passing on the baton”) and that continuing the TSS legacy research will ensure that the positive influence of that legacy continues and perhaps even increases. I recommend that the researchers carefully examine the content of the MIR studies being synthesized in Dr. Katz’s systematic review of the literature to identify the cited sources that motivated those studies. Those sources encapsulate the ideas that launched the search for explanations of the mistrust-in-research field.

References


Katz, R. V. (2015, March). Was the development of the mistrust-in-research (MIR) field of study yet another “legacy of the USPHS Syphilis Study at Tuskegee”? A case study in passing ethics research from “generation to generation.” Keynote address presented at the Annual Public Health Ethics Intensive Course, Tuskegee University, Tuskegee, Alabama.


Endarkenment is a term I have long employed to refer to the heritage of peoples of African descent. To be endarkened is to glean from, be nurtured within and transformed by the critical distillation of cultural wisdom found throughout Africa and the African Diaspora in ways organic and learned. The opacity of the experience of African women, children, and men in the transatlantic world context especially illumines the need for indigenous critique, cultural counter, sustainable lifeways and sacred alternatives to the imperialist capitalist white supremacist patriarchal forms of hegemony, which now demean life. For conceptualization, I have been inspired by a vast array of elders (and some not so elderly) from the above-named witnesses to my own mother and father and including but not limited to the artistry of Billie Holiday, Bessie Smith, John Coltrane, Mahalia Jackson, Lorraine Hansberry, Althea Gibson, James Baldwin, Nina Simone, James Brown, and including but not limited to the artistry of the O'Jays, Moms Mabley, Richard Pryor, Muhammad Ali, Marvin Gaye, Angela Davis, The Last Poets, Beah Richards, Julie Dash, Hale Gerima, Dianne Reaves, Sweet Honey in the Rock, Aretha Franklin, Stevie Wonder, Jill Scott, India Arie, Toni Morrison, Common, Nas, Mos Def, Aja Duvayen, and especially the many millions gone. The opinions represented in the article are those of the author.

Introduction

#Black lives matter! The first half of this essay is a historically-informed account of state-sanctioned violence and how structural racism and oppression continues to serve as a public health crisis requiring profound ethical analysis and just response. The canard of post-racialism is exposed against the current backdrop of violence, white supremacy, patriarchy, state power, imperial policing and more faced by people of African descent in the United States. If Black and Brown, male and female bodies are to contest “life in the valley of the shadow of death,” new visions that catalyze and connect people in sustainable and radical movement are required. Part two of this essay is a parable that envisions a movement from the margins and below to challenge our contemporary lethargy and dehumanizing of people. The call to consciousness and transgression, embodied in what the author terms “The Endarkenment” celebrates a new solidarity, envisions a new society, and demonstrates the power of Black lives as an ongoing praxis of love and freedom.

Historically-Informed

I was invited by the Huffington Post to write an essay for their on-line month-long series in February called “28 Black Lives that Matter.” My article paid tribute to Mr. Bernard Bailey, a relative unknown among the crush of national headlines and viral discussions recounting African American lives endangered and taken amidst circumstances that we wish had not taken place. I began my commentary with words that read something like this:

“The most defining moments in our lives often come like a thief in the night, quietly and unsuspectingly, preceded perhaps by premonition or foreshadowed by force of circumstance, but usually with little or no advanced warning. Such is the nature of the valley of the shadow of death experienced by people of African descent in the Americas for five hundred years. Today, much has changed; little has changed. Harsh and oppressive conditions, under the cover of new names, continue to short-circuit the life chances of many of Africa’s children in America. For African Americans, the specter of death is everywhere. Death and the conditions of death are the lived reality we contend with still.”

In the early morning hours of May 2, 2011, Mr. Bernard Bailey lost his life in a deadly encounter with the Police Chief of Eutawville, South Carolina. Mr. Bailey was 54 years old. He was unarmed. The altercation arose from an argument over a ticket for a broken taillight the chief had given to Mr. Bailey’s daughter a few days earlier. The date for her scheduled court appearance conflicted with her return to college. Mr. Bailey went to the Town Hall to discuss the citation on his daughter’s behalf.

Bernard Bailey was a well-known and highly respected member of the small Orange County community of some 300 residents. Mr. Bailey was shot three times, once in the shoulder and twice in the chest, as he backed out of the parking lot in an effort to escape a rapidly escalating situation. The Eutawville police chief was indicted on December 3, 2014, one week after the grand jury returned no indictments against a white officer in the death of unarmed Mr. Michael Brown in Ferguson, Missouri, and on the same day the grand jury produced no indictments in the chokehold death of Mr. Eric Garner, also unarmed, in Staten Island, New York. Unlike the other indictments, the shooting in Eutawville did not involve blatant allegations of race-related police misconduct. Still, this was the third white officer indicted in 2014 in South Carolina for the shooting of an unarmed Black man.

The family settled a wrongful death lawsuit against the city of Eutawville last year. The police chief was dismissed from his job. However, justice and peace are far from having been won. The criminal case against the former police chief languishes in the court system. Scars to the tiny municipality run deep. Spiritual trauma has impacted the entire village. An invisible veil hangs over the community. Healing has not yet come. Questions, anger and grief persist. Mrs. Doris Bailey, children Briana, Kayla, Porcha, Charity, and Bernard and a network of family and friends survive Mr. Bailey. Bernard Bailey is one whose life matters.
Why did I agree to write about Bernard Bailey? I did not know him. I have never been to Eutawville, South Carolina, located some fifty miles southeast of Columbia. However, we were the same age, he and I, we attended college in the same city (Nashville, Tennessee) and we graduated the same year. Bernard went to Tennessee State University and I attended Fisk University less than a mile away. Public and private, large and small, town and gown, athletics and academics, were some of the terms used to distinguish the two historically Black Universities, and our student bodies did not interact a great deal. However, if Bernard’s priorities as a college student in the least bit resembled mine, there is a chance we met at one of the many legendary parties that brought Fisk and TSU students together back in the day.

Most importantly to me, Bernard Bailey and I have children that are very close in age. We are both fathers. The tragic events that took place on that late night-early morning in May 2011 occurred because one devoted father’s fierce and wondrous love and care for his daughter was met by the sordid and horrific response of law enforcement to the same. There is no need to further rehearse the details of what happened that night. Suffice it to say, what was a routine traffic violation turned into systemic and senseless violence, and ended in a good man’s death.

The death of Mr. Bernard Bailey serves as a somber meditation and familiar lamentation on the diminished meaning of Black life in this land. At this year’s public health intensive (2015), I am glad to see the attention to blacklivesmatter. It is important we state for the record that racism by whatever name – white supremacy, discrimination, bigotry, inequality, disparity, hypocrisy, injustice, or greed – is a deadly assault on African American life. Were I to offer commentary from the biblical witness on the current climate of African America’s communal health it would come from the book of Job (3:26) in the Hebrew Bible: “For me, there is no calm, no peace; my tortments banish rest.” The trauma that Mr. Bailey experienced winds its way through the life and death experiences of our forebears, the children, women and men, so many millions gone; our great and unknown ancestral cloud of witnesses.

The profoundly cruel and color-coded legacy of Black suffering, sickness, abandonment and death is deep and longstanding in this land. The litany is familiar to us all: From the morose period of antebellum enslavement, post-reconstruction, and Jim Crow; the tragedy of the U.S. Public Health Service Syphilis Study at Tuskegee and the assassination of four little girls in Birmingham’s Sixteenth Street Baptist Church; the violence unleashed in “Selma, Lord, Selma” on Bloody Sunday and the Edmund Pettus Bridge; to gross disparities in communal health it would come from the book of Job (3:26) in the Hebrew Bible: “For me, there is no calm, no peace; my tortments banish rest.” The trauma that Mr. Bailey experienced winds its way through the life and death experiences of our forebears, the children, women and men, so many millions gone; our great and unknown ancestral cloud of witnesses.

For countless ages and peoples, the parable has been used as a means to express sacred truths. At its best, the parable instructs, disturbs and ultimately invites its hearers and readers into intimations of the wholly possible. The parable disorients our reality in order that it may reorient us. The parable is disarmingly simple and deeply memorable. The initial imagery into intimations of the wholly possible. The parable disorients our reality in order that it may reorient us. The parable is disarmingly simple and deeply memorable. The initial imagery

This is hardly to say that all Black sickness and death is attributable to the white world. Far from it. But cultural understandings, communal maturity, and identity formation in African America have long been imprinted with the intuited awareness that the United States is a nation built on hierarchies of oppression, with one group privileged above another, and individuals acknowledged each according to their rank. A person of African descent is assigned less value than someone of European extraction. Men are understood to be more important than women.

Stricts are morally superior to gays. The wealthy have more – and matter more – than the poor. Immigrants of recent vintage – Arab, Asian and Latin descended – have become too numerous and pose a threat to the empire’s design.

Tragically, African Americans, in our own miseducation “drank the Kool-Aid” and embraced the lie; we too have internalized America’s terrible untruths and come to undervalue ourselves. In spite of the nation’s misanthropic misdeeds, we know these words are true: To love ourselves deeply is at the heart of our own emancipation. We have the agency. We have the power. We bear part of the responsibility for our individual and collective choices even in the midst of the most death-dealing of social circumstances. In the words of Ida B. Wells-Barnett, we must “awake, arise, and act, no longer sleep and slumber, but distinguish ourselves.” We ourselves must live as if Black lives matter.

Self-empowered, we bear witness to the sacred worth of all persons, with the prophetic dedication of Dr. Martin Luther King, Jr. King described the United States as an extremely sick nation, fueled by the fires of privilege and disparity, injustice and hegemony, unrequited rage and greed. America produces a culture of incivility and death that diminishes and extinguishes the life chances of Black and Brown children, women and men, gay, transgender and straight, without respect to social class. It does so in alarming numbers, in public and private spaces, and thinks little of it as long as the violence can be carefully managed and contained.

Issues of life and death, love and loss, illness and health, are often embedded in indigenous religious and socio-cultural understandings and from such places some of our best public health interventions are yet to come. Today, the epidemic of dehumanization, disease and death that is perpetrated on Black and Brown bodies pervades the public consciousness and invades the public square. Our charge is to challenge the prevailing maelstrom, celebrate our sacred worth, and affirm the content of our character.

In some respects, we have come far where issues of social divide matter. In many ways, we appear not to have progressed at all. Out of the midst of the conditions of death, African America vividly and dramatically remembers, we critically and prophetically assess; we transgress against the pathos, power and predictability of the nation’s original sin. We remain committed to those material and spiritual life ways that preserve and enrich life itself. I come to you this afternoon as an ally in that quest for social change, sharing from a remarkable force for good, the insurrection of subjugated knowledge, presented unconventionally in the form of a parable.

For countless ages and peoples, the parable has been used as a means to express sacred truth. At its best, the parable instructs, disturbs and ultimately invites its hearers and readers into intimations of the wholly possible. The parable disorients our reality in order that it may reorient us. The parable is disarmingly simple and deeply memorable. The initial imagery is often gentle but soon dismays. The parable is at once understated and paradigm shifting, rupturing and revelatory, shattering complacency and disrupting the status quo; it gives new meaning. The parable unmasks the “objective standards,” “established norms,” and “canonical truths” of empire with exceeding power; it is counter-hegemonic. The parable makes manifest new knowledge and insights that challenge existing customs and cognitions; it changes lives. In the end these disruptive narratives, grounded in our experiences of the everyday and the familiar, give rise to a radically pragmatic hope that makes people whole and sets humanity free.
Instructive for our purposes are the parables of the African American literary tradition. African American wisdom literature (my terminology) is filled with many wonderful and provocative parables penned by Langston Hughes, Alice Walker, Octavia Butler, and Derrick Bell, among others. In my estimation, African American parables provide a resolute critique and transcendence of the extant social order. They help ensure the transmission of our values for survival won against all odds. They reclaimed their neglected sacred inheritance of community, what this minister holy taught her church. Through fervent and disciplined spiritual study, the members of this minister’s congregation were utterly transformed by the power of the Word that she shared. The Sankofa idea was simple and yet oh so exceedingly complex: “Return to your past in order to move forward.” Sankofa is term form the Akan of Ghana, West Africa. The words of ancestor, Al Hajj Malik El-Shabazz (Malcolm X) took on renewed meaning; “those who forget their history are doomed to repeat it.” They embraced the ancestral admonition of Ella Baker, who said, “Strong people don’t need strong leaders.”

After a few weeks and months of intense study the myriad marks of former oppression began to fall away from the congregation; an endarkened consciousness appeared. Not a particular religious doctrine, political philosophy, economic agenda or any other formulaic creed, but the seldom-embraced and even less remembered sacred heritage of her people was what this minister holy taught her church. Through fervent and disciplined spiritual study, these believers rediscovered that theirs was a proud legacy of from “sun up to sun down,” of survival won against all odds. They reclaimed their neglected sacred inheritance of community, mutuality, nurture, struggle, resistance, liberation, healing, identity and pride in “how we overcome.” They experienced anew in their faith (Imani) and in their lives what it means to be saved, not conventionally as “born again Christians” but more, as “born again African peoples.” (Karenga, 1998)

What these believers learned, remembered and reclaimed was their own transcendent sense of worth. They were the descendants of people whose primary motivation was not retaliation or revenge. They were the children of a people who did not wallow in self-pity, inferiority or despair. They were born of a people who did not hold each other down like crabs in a barrel. They emerged from a people who did not turn their anger on one another first, last or any other time. In this spirit, equipped with an endarkening faith, Black folk who had previously been willing workers became fountains of creative (Kuumba) activity now. Anointed with a magnificent obsession, their lives became the very embodiment of purpose (Nia). Others joined them. Black men, who were once known to congregate in back alleys and gather in unsavory places, and Black women who by virtue of circumstance were often in harm’s way, instead became the new architects of collective work and responsibility (Ujima). Word soon spread about the power of the people in this congregation, and the little church that could quickly outgrow its space.

At first, the church held its services in the sanctuary but was determined to spread the wealth even further, out in the clearings, to fully share the teachings in the spirit of unity (Umoja) with other faith and community leaders, and especially among the grassroots. The members became missionaries to the miseducated and evangelists to the emotionally and materially enslaved; they were spreading the good news about what it truly means to be saved. While the excitement grew in Black communities without respect of every religious communion the popular media with rare exception ignored what they interpreted as just another insignificant activity from an inconsequential group.

Soon and very soon, however, there was no ignoring what was taking place in Black religious communions across North America. Like the tongues of fire on the day of Pentecost (Acts 2:10), the transformation spread from one church to another, from one faith community to another, from one place to another, from the United States and Canada to the Caribbean and the Americas South and beyond to Africa and back again, to an entire believing people – one child, woman, man and community at a time. Addiction, defeat, sickness, death, abuse, confusion, distrust, crime, despair, and self-hate were no more – as every Black person sought to be “filled more with the spirit.” They were able to “speak in new tongues,” to study, learn and grow, to know self-determination (Kujichagulia), to excel in all things and “prove thyself worthy,” not in the eyes of a hegemonic deity, but a universal God.

The endarkenment spread. Black consciousness grew. The beauty of self-awareness had dawned. A healing was coming on. The unemployed found work. The underemployed redefined supply and demand. All manner of community enterprise was encouraged and flourished in the spirit of cooperative economics (Ujamaa). Black faith institutions became libraries, lyceums, laboratories, mutual aid societies, social media platforms and counter-public spaces as in the days of old when many things were done innovatively and in common. Many who had once been the recipients of public assistance programs began sending modest repayment checks to social service agencies.
Conclusion

Black family life strengthened as patriarchy, misogyny, heterosexism, homophobia, violence, non-commitment, and unwanted births became a thing of the past. Black men loved themselves in new and walk worthy ways, reveling in their Black sisters, revering their Black brothers; they were no longer low down and no more living on the down low; they were keeping it real and keeping it right, assuming responsibility for raising their own beautiful Black children. Black women, meanwhile, loved as they had always loved, and will always love, with a magnificent love that would not let their Black brothers and sisters, mothers and fathers, children and elders go. Black same-gender-loving women and men were loved without stigma and loved unreservedly, they were loved in their own right and they in turn loved, and rejoiced to be loved and received among their own kith and kin at last. Black elders were respected, honored and cherished for their knowledge, goodness and wisdom and they taught the children well. Black children loved themselves, honored their parents and families, respected each other, excelled in academics and attended newly opened community classes held in now empty juke joints, pool halls, crack houses and taverns. Black people of every gift and ability were affirmed without exception and a positive self-identity was extolled by all. By making our separate past a present source of strength, a new generation of women and men were being prepared to become the leaders and lovers of us all.

But that was not all. Believers also formed a spirited Black-led movement to eliminate poverty, inequality and despair among the growing ranks of the disenfranchised and disenfranchised in every community. Blacks were second to none and primus inter pares – first among equals – by every indicator and in every arena.

For much of the white world it was absolutely unfathomable, unsettling, unpatriotic, undemocratic, Blacks not engaging in chronic crime, pathological wrongdoing, internecine violence and self-destructive behavior. The crack, tobacco, beer, malt liquor, pharmaceutical and pork rind industries went under for lack of customers. Beauty supply stores and nail salons came under new ownership. Convenience stores, shopping malls, the five and dime, restaurants, and service stations, these too developed a new look and a new attitude. The health care, fast food, casino, games and funeral industries faced a new crisis as black people became nutritionally, emotionally and spiritually whole and of one piece.

Affirmative action was discarded as powerful new coalitions with progressive whites, Asians, Latino/as, Native peoples, lesbians, gays, transgendered, the working poor, the poorest of the poor, the unruly poor, society’s ignored, “the least of these,” were forged and the earth itself was once again held inviolable and sacred. The criminal justice system fell into disorder, despair, and finally disrepair as penal institutions were transformed into empowerment zones, as jailhouses, prisons, detention centers and halfway houses became campuses of higher learning. Black men were transformed en masse by the new movement in the Black community. Black children were transformed as the criminal justice system fell into disarray, desertion, and despair, as penal institutions transformed into empowerment zones. As jails and prisons and detention centers became campuses of higher learning, Black men were transformed en masse by the new movement in the Black community. Women, who had always been the child carriers, burden bearers, heavy load sharers, cultural transmitters, mules of the world, rocks of Gibraltar, pillars of faith, our all in all, were finally and at last able to exhale.

Christians, Muslims, people of all faiths and no professed religious faith at all were as one. No more surrender, no more self-doubt, no more fear, no more emasculation, no more domestication, no more emulation, no more intimidation, no more incivility, no more disrespect, no more thieves in the temple, no more entertainment that passes for religion, no more demeaning young people, no more disrespecting elders, no more abandoning families, no more violence, no more sexism, no more misogyny, no more homophobia, no more heterosexism, no more patriarchy, no more misanthropy, no more Black-on-Black death, no more global warming, no more desecration of the earth, no more ethnocentrism, no more colorism, no more hatred, no more apologies, no more internalized oppression, no more fatalism, no more feeling sorry for ourselves, no more time for excuses, no more the abuse, no more the lies, no more, no more.

“The stones that the builders rejected” – African descended children, women and men – had turned to building a new city, one not made by hands. The faithful called it by many names: the new heaven and the new earth, the new Jerusalem, the promised land, Mecca, Zion, a place of peace, the global village, the world house, the reign of God, sweet communion, and the common wealth, where all there is, is One. They had become Africa’s Praise song, Mahalia Jackson’s Whole World, Bob Marley’s One Love, Public Enemy’s Black Planet, Aretha’s RESPECT, Queen Latifah’s UNITY, Third World’s Children of the World, Audre Lorde’s common cause, Desmond Tutu’s rainbow people, Martin Luther King Jr’s beloved community. Change does not wait for some other person or some other time. In the insurgent words of Sweet Honey in the Rock and adopted by then Senator Barack Obama: “we are the ones, we are the ones, we’ve been waiting for.” Endarkened, empowered, enabled, emboldened, embracing, including – we are the ones, our “own best selves,” the very embodiment of the presence of God. Amen. Amin. Ashé.

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All Our Relations: Assuring Tribal Research Ethics from Generation to Generation

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Author Note
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Abstract
This article includes the content of a presentation given at the Tuskegee Annual Commemoration & Public Health Ethics Intensive Course focused on the question of what it will take to assure ethics from generation to generation in research in the context of tribal nations. It concludes with an emergent case of how the National Congress of American Indians is stewarding ethics in responding to the revisions to the Common Rule.

Keywords: ethics, tribal nations, research governance

Introduction
What will it take to assure ethics from generation to generation in research? In March 2015, the Tuskegee Annual Commemoration & Public Health Ethics Intensive Course was convened to consider this question. In responding to this question, Malia Villegas, Director of the National Congress of American Indians Policy Research Center developed a presentation around learnings from a partnered effort to strengthen tribal research capacity and celebrate Indigenous knowledge in research. This manuscript includes the content of that presentation, as well as information from an emergent case that demonstrates one opportunity to assure research ethics in revising the Common Rule.

The primary learning presented is that assuring ethics from generation to generation with tribal nations requires a constant engagement with what it means to be a good human being. Being a good human being is a concept that comes out of some Indigenous cosmologies and represents an understanding of role and relationship in the cosmos. In the context of assuring research ethics, a constant engagement with what it means to be a good human being must involve regular discussion about:

1. How we tell our stories to ourselves and about ourselves;
2. How we understand our responsibilities to each other and to life in all its forms; and
3. How we honor our relationships to ourselves and to each other.

In what follows, we describe our work to foster this constant engagement and strengthen the foundation of relationship that must form the center of any robust, long-standing system of research ethics.
Telling Our Stories to Ourselves and about Ourselves

In 2009, the National Congress of American Indians Policy Research Center developed a curriculum to improve tribal research called, “Research that Benefits Native People: A Guide for Tribal Leaders”. This five module course is provided over two-and-a-half days at the invitation of tribal nations to assist with establishing tribal research oversight processes. One of the curriculum modules focuses on research ethics. These modules are based around five core research values, including:

1) Indigenous knowledge is valid and should be valued.
2) Research is not culturally neutral.
3) Responsible stewardship includes learning how to interpret and understand data and research.
4) Tribes must exercise sovereignty when conducting research and managing data.
5) Research must benefit Native people.

While this module provides information on the Belmont report and the three principles of respect for persons, beneficence, and justice that form the core of U.S. research ethics, we start this module by discussing with tribal leaders what values and principles form their own community ethic. For example, in one tribal nation, we discussed how a respect for life in all its forms (e.g., human, plant, and animal life) is an essential value in their culture and could drive their research policy.

Naming the community’s own ethic is essential for ensuring that research processes are driven by a set of values that resonates across a community and can be anchor points in times of development and difficulty. For instance, in American Indian and Alaska Native research and policy, there is a pervasive narrative that emphasizes what Native peoples and our cultures “lack”, often to the exclusion of recognizing any community or cultural strengths. Gaps in achievement, health outcomes, and employment lead any headlines and feed a narrative of scarcity that generates a particular type of research culture that often ignores the role of culture. When tribal nations embrace and articulate their own values, we can work with them to leverage their strengths and even foster more Native-to-Native comparisons that share strength and build capacity from one nation to another.

In fostering a shift in narrative, we hosted a Native Youth Data Institute in summer of 2014 and invited a range of Native youth to help us tell different stories than are often told in research studies, public health investigations and clinical testing conducted by the U.S. Public Health Service and Alaska Native tribal health organizations dating back to 1961…85% were collected from Alaska Native people” (p. 1). In order to assure the ethical and meaningful use of decisions made by tribal oversight bodies in their research codes – to highlight how values inform policy, which further inform decision-making process. In this way, tribal research ethics stand as an ongoing engagement with cultural values and governance policy.

Our work with tribal leaders led to a research project with scholars at the University of Washington and the University of New Mexico about what contributes to effective community-based participatory research where we learned that culture, governance, and trust are essential pillars in strong tribal-academic research partnerships. In partnership with Dr. Julie Lucero at the University of Nevada Reno, we have developed a toolkit to equip tribal-academic research partners in strengthening their relationships using these insights. For instance, we talk with partners about the importance of understanding cultures of guests and cultures of hosts in tribal research. Understanding these cultures requires awareness of local values and protocols and of expectations by both partners. Having a process to regularly engage with who you are, how you understand your role, and the values in place where research is developed is essential for ensuring a strong community ethic of research.

Such an approach embodies a commitment to tribal sovereignty in research – an awareness of the responsibility tribal nations have to steward research on their lands and with their citizens in a way that benefits their people. In fact, our work has led to a nuanced way of understanding tribal research governance that could inform how we understand the nature of research ethics in the U.S., which in many ways has been narrowed to research regulation and embodied as the moment of approval by an Institutional Review Board rather than a regular engagement with a principled process. Assuring ethics from generation to generation requires understanding research governance as stewardship instead of regulation.

Coming to view research governance as stewardship is particularly important in the context of emerging technologies like genetics research. In the summer of 2014, NCAI partnered with the Smithsonian’s National Museum of the American Indian and the National Human Genome Research Institute of the National Institutes of Health to present a one-day symposium featuring perspectives from tribal leaders and Native scholars on genetics research. Videos of the four panel discussions from “A Spectrum of Perspectives: Native Peoples and Genetic Research” are available on NCAI’s website. As part of this discussion, we observed the range, or spectrum, of perspectives that tribal communities are weighing when considering their participation in and partnership in genetics research. Where some like the Navajo Nation have issued a moratorium on genetics research, others are proceeding with caution and interest in this research might offer new technologies like pharmacogenomics to fight diseases like leukemia. In other places, Native communities have created state-of-the-art biobanking repositories to enable research including that involving genetics like the Alaska Area Specimen Bank, which as of 2013 was reported to contain “266,353 residual biologic specimens (serum, plasma, whole blood, tissue, bacterial cultures) from 83,841 persons who participated in research studies, public health investigations and clinical testing conducted by the U.S. Public Health Service and Alaska Native tribal health organizations dating back to 1961...85% were collected from Alaska Native people” (p. 1). In order to assure the ethical and meaningful use priorities. As part of delivering the NCAI curriculum, we guide tribal leaders in using their values to drive research policy development that is grounded in cultural ethics. Taking a note from our neighbors to the North in Canada, we illustrate how the “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans” incorporates both policy statements and actual applications of these policies. We encourage tribes to include actual cases of decisions made by tribal oversight bodies in their research codes – to highlight how values inform policy, which further inform decision-making process. In this way, tribal research ethics stand as an ongoing engagement with cultural values and governance policy.
of these specimens, there is a layered oversight process in place with representatives from tribal, state, and federal health organizations engaging as part of a working group using policies and protocols developed together.

Community governance of research can lead to more robust and useful outcomes. Yet, to get there, partners must start from a place where we view community leaders as gatekeepers and community engagement as more than a gateway to higher numbers of participants. Federal research policy is explicitly framed to minimize and prevent researcher burden where individual and community consent, local oversight and review, and the return of results are described.

In order to plan effectively and to strengthen the health and wellness of their citizens, the National Congress of American Indians (NCAI) asserts that tribes have sovereignty over research that happens on tribal lands and with tribal citizens, including those living off tribal lands.

Martin Yarborough, Director of the Center for Bioethics and Humanities at the Colorado School of Public Health, University of Colorado, Denver, and several colleagues writes about the differences in how biomedical research institutions foster institutional cultures of safety, cultures of integrity, and cultures of trustworthiness. In their work to investigate the important strategies for fostering the public’s trust in research institutions, they note that it is essential to foster “multiple types of relationships” and develop “accountability practices that exceed those required by external regulators” or self-regulation. Authors lament the shift by federal funding and regulatory agencies toward compliance, driven by incidences of fraud, ethical violations related to non-disclosure of financial and other conflicts of interest, and deaths of research volunteers. Public awareness of the local relevance of the research enterprise was also cited as a key aspect of fostering trust. Authors call for an expanded accountability as “current norms of accountability in biomedical research are based largely on adherence to the scientific method itself, along with professional norms, peer review, IRB oversight of human subjects research, and disclosure of financial conflicts of interest” (p. 574). As a framework for research governance, stewardship is characterized by a distinct accountability for decision-making that is informed by locally relevant values and priority outcomes because stewards are those that are often related to and elected by the communities they serve and thereby especially responsible for the outcomes of their decisions. In this way, “all of our relations” drives decision-making and serves as the foundation for a system of ethics that defines our roles and responsibilities to each other.

Understanding Our Responsibilities to Each Other and to Life in All Its Forms

Research can be a key lever for tribal leaders to use in exercising tribal sovereignty in order to plan effectively and to strengthen the health and wellness of their citizens. The National Congress of American Indians (NCAI) asserts that tribes have sovereignty over research that happens on tribal lands and with tribal citizens, including those living off tribal lands.

Governance in research relates to establishing a process of decision-making that results in meaningful outcomes for communities. Meaningful outcomes are those that have real benefits and that have been generated in an ethical and appropriate way. In the work that NCAI has developed with community leaders, academic partners, and federal agencies, we have found that research partners may not always have the same perspectives on the nature or role of governance in research. This is due in part because there are a range of different understandings about the purpose and process of decision-making.

One of the central elements of tribal sovereignty is that each tribe decides how to enact its own sovereignty. As such, while tribes may have sovereignty over research that happens on their lands and with their citizens, the ways that they enact their authority and responsibility may look different from one tribe to the next. A number of tribes have established research codes that define their governance authority and responsibility and often designate a process where oversight of research is often designated to a tribal committee or department, while in others tribal councils retain the oversight authority. Yet, it is important not to assume that tribes that have elected to have tribal councils make all research decisions have done so instead of establishing a more comprehensive review process. Some tribes have extensive research oversight protocols, but choose to have the full council make decisions about all research. In the absence of research codes, however, it is essential that researchers interested in partnering with tribes reach out to the tribal council to determine what the process for partnership will be. Efforts to circumvent the tribal council and engage directly with tribal members violate tribal sovereignty and foster research that may be unethical and inappropriate. Just as it is important for academic partners to honor tribal sovereignty, it is important for tribal nations to set out a sustainable protocol for research partnership and oversight if they value the role of research in community planning. If tribal council approval is the only protocol specified, there may be challenges to sustaining research partnerships and oversight when there is high turnover of tribal council leaders.

One of the key questions for partners to consider in thinking about how sovereignty matters in research is, when does governance take place? It is important for research partners...
to consider whether they view governance as a “moment in time” or a process that occurs over time. For instance, does governance take place only during the moment when the tribal council (or other vested entity) decides to approve or not approve a research proposal? Does governance take place when the parameters of research design and outreach to research participants are being negotiated? Does governance take place only during times of conflict? Does governance take place over the course of the research project? Governance is an ongoing process of relationship and responsibility that must be nurtured.

However, when governance is limited to the moment of “approval”, there is no sustained relationship and conflict fueled by misunderstanding persists. One of the most persistent tensions in the context of tribal research governance is the perspective that tribal councils are gatekeepers, preventing researchers from accessing American Indian and Alaska Native people to participate in research or creating more burdens on researchers constraining research partnerships from developing. This perspective can stem from the related belief that tribal councils are merely gateways for researchers to recruit more and diverse research participants. With this perspective, governance is limited to research regulation and community oversight bodies afforded only a regulatory role.

When we constrain governance to regulation, its purpose is framed as a tension between either preventing harm to humans or limiting excessive burdens on researchers that limit scientific innovation, where we can never fully achieve both goals. This stems from an understanding of governance as authority and power rather than responsibility for outcomes. A process where partners articulate and find a way to connect hoped-for outcomes can inform a process of achieving these outcomes in an ethical way. But if partner engagement is viewed as burdensome from the outset, the process that emerges will be plagued.

This sort of framing can also lead to a very slippery slope where upholding essential ethical principles in research is seen as burdensome. Consider that in the recent request for comments in revising the Common Rule, there is explicit language that asks how best to “tradeoff” ethical principles that form the foundation of research ethics in order to revise the definition of human subject. Question 4 asks, “Which of the three proposals regarding the definition of human subject achieves the most reasonable tradeoff between the principles of autonomy (including transparency and level of trust) versus beneficence (as measured by facilitating valuable research)?” (p. 53946). While it may be important to balance a range of ethical principles, when we begin considering tradeoffs of our ethics, we not only constrain our ability to protect humans, but also open the possibility that harm to humans is allowable.

Throughout the proposed revisions, there is a concern that unnecessary burdens on researchers (or “investigators”) constrain research innovation, but we are left wondering about the nature of these burdens – is it too much burden to expect that potential research participants be asked for their consent to use their information and biospecimens? When did consent become such a burden? Was it when research with large or “big” datasets became a priority? When information technology advanced in significant ways? According to the rationale presented for “modernizing the Common Rule” on page 53938 of the NPRM, advances in technology create much of the need for these proposed revisions:

The advent of sophisticated computer software programs, the internet, and mobile technology has created new areas of research activity, particularly within the social and behavioral sciences. In biomedical science, the Human Genome Project laid the foundation for precision medicine and promoted an environment of data sharing and innovation in analytics and technology, and drew attention to the need for policies that support a changing research landscape. New technologies, including genomic sequencing, have quickly led to exponential growth in the data to which investigators have access. The sheer volume of data that can be generated in research, the ease with which it can be shared, and the ways in which it can be used to identify individuals were simply not possible, or even imaginable, when the Common Rule was first adopted.

Yet, we would rather promote a revised policy that diminishes responsibility for protecting human subjects and ethical tradeoffs instead of using this advanced technology to facilitate consent? By removing the burden of asking for permission, will the gateway to research innovation somehow be opened? This rationale echoes a time in the past when the research community made the most severe violations against humans and prompted the very policy that we now aim to revise.

It is important for research partners to reflect individually and over time about how they view the role of tribal councils or other community entities with research oversight responsibility. Tribal leaders have unique scientific insight to contribute that could strengthen research findings and results. Tribal leaders have unique cultural insight to contribute that could strengthen research findings and results. And there are lessons from research with American Indian and Alaska Native peoples that could inform planning and wellness for other communities. NCAI has found that when tribal councils are viewed as critical guides over the course of a research project, partnerships can be strengthened and research results can be meaningful.

We must not only articulate our responsibilities to one another as research partners, but as communities with overlapping and connected genealogies. African American and Native American people need to acknowledge our relationship for our own edification, but also to prevent the insidious nature of policy designed to divide and conquer.

Standing Rock Sioux scholar Vine Deloria, Jr. (1969) analyzed the different patterns of acculturation between Native peoples in the U.S. and African slaves and their descendants in his chapter entitled, “The Red and the Black”. Deloria explains that African slaves and their descendants faced exclusionary policies, while Indigenous peoples faced assimilation policies. He asks why one group was forced to remain outside of the bounds of everyday White society, while the other was forced to participate in ways deemed appropriate by those Whites in power. His answer is that the “Red” had access to land, while the “Black” did not, though I would argue that the labor of African slaves and their descendants fueled the rise of the U.S. economy.

Following Deloria’s logic, the U.S. government could afford to exclude Blacks, and yet it needed a system to break down the tribalism, collective sharing, and community use of land and its “resources” amongst Native peoples to establish the country as a unified, new, and growing nation. Picking up this argument that links the need to assimilate Native peoples with the strength of the new American nation, other scholars explain how efforts were made to frame Native peoples as part of a primitive and long gone history to justify the philosophy and practice of Manifest Destiny (Adams, 1988/2008; Lomawaima & McCarthy, 2006). Manifest Destiny is the idea that God ordained western expansion into North America because its lands were uninhabited and thus ripe for taming and settlement (Adams, 1988/2008).
Around the turn of the 20th century, images of the vanishing Indian race proliferated (see for example the photography of E. S. Curtis or the compelling description of this phenomenon in B. W. Dippie's 2007 The Vanishing American: White Attitudes and U.S. Indian Policy, University Press of Kansas). The "logic" here was that if there were Indigenous groups legitimately claiming to be prior inhabitants of the land, U.S. claims of nationhood could be challenged. So, Native peoples and their cultures were deemed savage, primitive, and dying to further the needs of the new nation. Of course, neither the West nor the Americas were uninhabited, and Native peoples had not vanished. So, in addition to advancing ideas about the "vanishing Indian race," the U.S. government needed a system that would assimilate American Indians and Alaska Natives quickly – one that would categorically replace one set of values for another deemed more appropriate to national goals. Schooling became that system. In this way the value conflict between cultures is rooted in contexts of knowledge, education, and training. A fact that continues to impact the conduct of research, research partnerships, and research training.

These conflicts are fueled by narratives where urban issues dominate calls for equity and justice to the exclusion of rural needs or in ways that obscure the fact that urban populations include African American and other communities of color. The diversity of our experiences is a strength, but the range of these experiences must be made visible. In addition, the ways that place matters must be understood in order to draw on our diverse strengths. One of our Yup'ik Elders, Angayuqaq Oscar Kawagley, talked about the importance of understanding who we are as Arctic peoples – how we live, the languages we speak, and the ways we relate to the Arctic world. In the same moment, we need the people of Brazil to be who they are and speak their languages because we do not know what they know about stewarding their places like they do. In this way, deep knowledge in place informs global connections and relationships where biological diversity is essential to maintain.

In our work at NCAI with tribal nations, we have seen how deep awareness about the realities facing Native people can inform the ways we shape policy for other communities. For instance, in some places, our population can be very mobile, particularly Native youth and families. Trying to estimate the size and nature of their mobility has indicated the need for better measures and methods to collect data from mobile populations. It has also contributed to reviewing programs like migrant education to determine if there are insights there that could be used to benefit Native youth who are mobile in similar ways. In addition, the fact that so many grandparents are involved in raising their grandchildren has contributed to the need for more complex understandings and analysis of head of household data – a trend that may be important toward that process, we present insights below about how we engage the process to revise the Common Rule. We assure ethics from generation to generation by investing in an ongoing process toward that process, we present insights below about how we engage the process to revise the Common Rule. We assure ethics from generation to generation by investing in an ongoing process to establish a tri-partite statement of ethics in Indigenous research. If we view the Common Rule as a baseline of ethics, we could strengthen the enterprise of research by setting a standard from national statement of community ethics. Canada, New Zealand, and Australia have worked to establish a tri-partite statement of ethics in Indigenous research. If we view the Common Rule as a baseline of ethics, we could strengthen the enterprise of research by setting a standard from national statement of community ethics. Canada, New Zealand, and Australia have worked to establish a tri-partite statement of ethics in Indigenous research. If we view the Common Rule as a baseline of ethics, we could strengthen the enterprise of research by setting a standard from national statement of community ethics. Canada, New Zealand, and Australia have worked to establish a tri-partite statement of ethics in Indigenous research. If we view the Common Rule as a baseline of ethics, we could strengthen the enterprise of research by setting a standard from national statement of community ethics. Canada, New Zealand, and Australia have worked to establish a tri-partite statement of ethics in Indigenous research. If we view the Common Rule as a baseline of ethics, we could strengthen the enterprise of research by setting a standard from national statement of community ethics. Canada, New Zealand, and Australia have worked to establish a tri-partite statement of ethics in Indigenous research.

Honoring Our Relationships with Ourselves and Each Other

Honoring our relationships involves shifting the gaze from a fiscal return on research investments to generating meaningful outcomes for communities. We must actively consider that there may be outcomes that could benefit us all rather than a sense that there is no interest convergence. One applied way we might identify shared outcomes could be to collaborate on writing our own Requests for Proposals or Funding Opportunity Announcements. By doing so, we could determine how best to represent shared research needs and priorities and encourage research institutions to invest in research of significance to our many communities.

In order to identify outcomes that may benefit many, we must invest in cross-cultural communication and engendering trust. Acculturation and assimilation are not generative goals. Instead, it is essential to explore and understand the role of culture and place in bringing about outcomes of value. Expanding cross-cultural understanding requires improving our knowledge of ourselves and the other. One way to do so might be to develop comparative metrics and studies to identify what we share and what aspects of our experiences might be more particular. In our work at NCAI, we have found that gap-based comparisons – where we consider the achievements on health outcomes between Native youth and non-Native youth – serve a purpose in drawing attention to unmet needs, they do not enable strengths-based analyses. To get to strengths, we have begun to create Native-to-Native comparisons to identify what some communities do well and how to leverage those strengths to similar communities. Developing comparative metrics across communities could aid in getting to shared outcomes and deeper understandings of particular characteristics.

To conclude, Villegas challenged symposium participants to consider co-creating a national statement of community ethics. Canada, New Zealand, and Australia have worked to establish a tri-partite statement of ethics in Indigenous research. If we view the Common Rule as a baseline of ethics, we could strengthen the enterprise of research by setting a standard from a community perspective – to hold research accountable to benefit community goals. To move toward that process, we present insights below about how we engage the process to revise the Common Rule. We assure ethics from generation to generation by investing in an ongoing process of articulating what our responsibilities are to ourselves, one another, and life in all its forms.

A Case Study: Assurance of Ethics for American Indians and Alaska Natives through Federal Policy Revision and Consultation

The Case – Notice of Proposed Rulemaking Comment Submission

The National Congress of American Indians (NCAI) is the oldest and largest national organization representing the interests of American Indian and Alaska Native (AI/AN) tribal governments in the United States. As a membership organization, NCAI serves the interests of the 567 federally recognized tribes, state-recognized tribes, and AI/AN tribal citizens in the US.
to affirm tribal sovereignty and secure Native peoples’ ability to prosper. In this work, NCAI has acknowledged that research driven by tribal leaders and developed in an ethical, meaningful way, adds value to tribal communities. As such the NCAI Policy Research Center (PRC) was established in 2003 to serve as a tribally driven center focused solely on issues facing tribal communities. The PRC asserts that tribes have sovereignty over research occurring on their land and with their citizens, and that research ethics must acknowledge the need to both protect and benefit Native people through research development.

To support NCAI’s mission, the PRC has ensured that the interests of tribal nations and peoples are recognized within requests for public comment on federal research policies. The PRC submitted comments in response to the Advance Notice of Proposed Rulemaking (ANPRM) that initiated a process to revise the Federal Policy for the Protection of Human Subjects (45 CFR 46), also known as the “Common Rule”, in 2011 and the National Institutes of Health (NIH) request for comments on their proposed Genomics Data Sharing Policy in 2013. Each of these comments served as a foundation for a response to the recent Notice of Proposed Rulemaking (NPRM) released in September of 2015, which describes “revisions to modernize, strengthen, and make more effective the Federal Policy for the Protection of Human Subjects that was promulgated as a Common Rule in 1991”.

The NPRM, with revisions proposed by approximately 19 federal departments and agencies, spanned more than 500 pages of text and presented 88 specific questions and cost evaluations for public comment. The original deadline for submissions was set at December 7, 2015 – allowing a total of 90 days for organizations to become aware of the notice, review the proposed changes, consider possible implications, and submit meaningful comments. The NCAI PRC worked diligently to draft comments for submission on behalf of tribal nations and AI/AN citizens, and to raise awareness of the comment process through various networks. A NPRM Comment Resource, which included a draft of NCAI’s comments and links to other resources about the proposed revisions, was developed to assist tribal nations and organizations in understanding the implications of the NPRM. A template letter was also created for interested parties to use in development of their own submissions.

In late November 2015, following repeated requests from various institutions for a deadline extension, the US Department of Health and Human Services announced that 30-days would be added to the comment period for a final deadline of January 6, 2016. Also, on December 21, 2015, a letter was distributed to tribal leaders to announce a Tribal Consultation conference call on January 5, 2016 – one day prior to the final deadline for submission of public comments. During the roughly one-and-a-half hour Tribal Consultation call, Dr. Jerry Menikoff, Director of the Office of Human Research Protections, gave a brief presentation on the proposed revisions to the Common Rule, and the tribal leaders able to join had an opportunity to comment and ask questions. By the final NPRM public comment deadline, NCAI along with approximately ten tribes, tribal organizations, and researchers engaged in work with tribal communities, had submitted comments.

Over the course of NCAI’s development and submission of NPRM comments, important tensions emerged with respect to both the Common Rule revision process and NPRM content. Understanding the pressure points related to the revision process sheds light on opportunities to strengthen federal-tribal engagement and thereby support tribal sovereignty within federal research policies and practice. Insights with regard to the NPRM content on the other hand, serve to redirect a focus on the burden of federal research policy toward a focus on ethics. Together, these lessons provide hope that research conducted with future generations of tribal peoples will occur in an ethical manner.

NPRM Revision Process – Tensions and Lessons

Two areas of tension surfaced within the Common Rule revision process related to tribal consultation and timing of the comment period. These tensions, and their associated lessons, are summarized below.

As noted, the 2015 release of the NPRM followed a revision process that began in 2011 with the ANPRM. There are significant implications for research with tribal nations and AI/AN peoples in the proposed revisions to the Common Rule and, while these revisions have been taking shape for years, the federal government has yet to establish an adequate parallel process of consultation with tribes. In a 2009 Memorandum to the heads of executive departments and agencies President Barack Obama stated, “The United States has a unique legal and political relationship with Indian tribal governments, established through and confirmed by the Constitution of the United States, treaties, statutes, executive orders, and judicial decisions. In recognition of that special relationship, pursuant to Executive Order 13175 of November 6, 2000, executive departments and agencies (agencies) are charged with engaging in regular and meaningful consultation and collaboration with tribal officials in the development of Federal policies that have tribal implications, and are responsible for strengthening the government-to-government relationship between the United States and Indian tribes”.

From the perspective of many tribal entities, a public comment period and brief conference call, labeled as Tribal Consultation and conducted more like a listening session, are no substitute for direct tribal consultation on policy revisions that will significantly impact the regulation and conduct of research with tribal nations and AI/AN citizens. Undoubtedly, the reach of the proposed Common Rule revisions outlined in the NPRM extends beyond AI/AN peoples, and efforts to revise such a far-reaching and important policy are necessary and commendable. Yet, the tension around tribal consultation on the NPRM, or lack thereof, highlights a need to remind federal agencies of their responsibility to consult with tribes and clearly carry out consultation processes. Efforts to define and differentiate between comment periods, listening sessions, advisory meetings, and consultation will facilitate federal-tribal engagement that will uphold the sovereign status of tribal nations and make it more likely that policies impacting tribal peoples will be developed and enacted in an ethical manner.

The rushed timeline of engagement with tribal nations – evidenced by a two-week window between distribution of a letter announcing the Tribal Consultation call to tribal leaders and the actual call, which was scheduled to occur only one day prior to the public comment deadline – is indicative of a larger concern around the timeline for the NPRM. The public comment period was originally a short 90 days, from early-September to early-December. Even with the 30-day extension granted in late-November, a large portion of the comment period coincided with the holiday season leading many to feel that the timeline for response to such a lengthy and important document was particularly compressed. Top-tier research institutions, with ethics departments and staff well versed in research regulation, requested...
Tensions related to the content of the NPRM provided two key lessons. First, many of the challenges within the proposed revisions could benefit from the addition of language extensions to the comment period. How then, could smaller institutions and organizations, many of which operate with limited resources and capacity to serve some of our nation’s most vulnerable populations, be expected to provide meaningful responses?

In the case of tribal nations in particular, formal research regulatory bodies are fairly rare. Furthermore, as sovereign nations, tribal statements on federal policy often require consideration and approval by tribal governments – a process that can be quite lengthy itself. The roughly 10 NPRM comment submissions from tribal bodies (including tribal nations, tribal-serving organizations, and researchers engaged in research with tribes) represent a small but engaged fraction of the diverse tribal perspectives throughout the US and underscore, again, the important role of tribal consultation to ensure that tribal needs are represented in federal policy. Several other tribal nations contacted NCAI to determine if NCAI was submitting comments and reviewed draft comments as part of the process.

Tension around the NPRM timeline also relates to a concern raised in NCAI’s comment submission about language used in the NPRM to describe that several of the proposed revisions were arrived at based on the “majority” of comments received at various points in the process of amending the Common Rule. Compressed comment timelines coupled with little outreach to groups with limited capacity to engage in such processes, make it difficult to imagine how the voices of smaller, marginal groups might eventually be represented in federal policy. The Common Rule, based on the Belmont Report’s principles of justice, beneficence, and respect for persons, is in place to protect all human participants in research. In the future, policy. The Common Rule, based on the Belmont Report’s principles of justice, beneficence, and respect for persons, is in place to protect all human participants in research. In the future, federal agencies must put in place mechanisms for outreach to marginal groups and recognize that public comment timelines need to account for such outreach efforts.

The comments were framed around implications of the revisions for research with tribal nations and AI/AN peoples related to consent for secondary research with biospecimens, consent for research with biospecimens or other data from people who are no longer alive, research oversight by tribal Institutional Review Boards (IRBs) and other tribal regulatory bodies, and research oversight for categories of research and activities important in tribal contexts.

With regard to tribal and individual consent for secondary research with biospecimens, NCAI noted that revisions calling for a broad consent for future, unspecified research use of biospecimens challenge the ongoing ability of both tribes and individuals to choose to remove their data from research, or to understand how their information is being used to benefit, or put at risk, themselves or others. Past violations of consent related to secondary research with biological data in AI/AN and African American communities were cited as evidence of the need for deeper ethical conversation about the appropriate use of biological data for secondary research purposes.

NCAI also emphasized the need to address protections for biospecimens initially collected from living humans after those humans pass away. Implications related to this aspect of research with biological specimens were heavily addressed in NCAI’s comments to NIH in response the draft Genomics Data Sharing Policy in 2013, and despite the fact that revisions proposed in the NPRM provide a level of oversight that did not previously exist for secondary use of de-identified biospecimens, NCAI’s concerns remain relevant with regard to the Common Rule revisions.

The third area of implications addressed by NCAI focused on the NPRM’s promotion of a single IRB in cooperative and multi-site research. This proposed revision was highlighted as an area of the NPRM that falls short of fostering community-based governance and oversight of research that has the potential to improve outcomes for tribal and minority populations. NCAI called for the addition of specific regulatory language that would direct research involving tribal nations to a process that includes, at minimum, an initial review by a tribal entity (e.g., tribal IRB, Research Review Board, or governing body), noting that the proposed revisions aiming to shift oversight and responsibility from research institutions to individual investigators coupled with promotion of single IRBs in multi-site research could have an unintended consequence of placing tribes and other communities at greater risk due to a lack of community governance or enforcement of research ethics.

Last, NCAI noted that proposed changes related to the exclusion of certain categories of activities, addition of exempt categories of research, and elimination of continuing review requirements for some studies could potentially remove research protections for activities that are common and important for the protection of sensitive information in tribal research contexts. The comments described that tribal research review often extends the scope of examination beyond individual-level protections to provide community protection, and in some cases all proposed research as well as subsequent presentations and publications are reviewed. NCAI expressed concern that the proposed revisions would not only impact the role of existing tribal research regulatory bodies, but also possibly have larger impacts for tribal communities with no formal review process.

Tensions related to the content of the NPRM provided two key lessons. First, many of the challenges within the proposed revisions could benefit from the addition of language...
that specifies the right of tribal nations to provide protections and processes that go beyond the Common Rule provisions in order to protect tribes and AI/AN citizens engaged in human subjects research. Second, the Common Rule must ensure an adequate level of protection for tribal nations and AI/AN citizens regardless of whether a tribal research review process (i.e., local tribal IRB or other research review body) exists to provide additional oversight. These lessons do not override the need for tribal consultation on the revisions moving forward; however, they do present a practical strategy and approach for further consideration by federal officials responsible for ensuring that the rights of all human research participants are protected under the Common Rule.

Remaining Issues

With the close of the NPRM public comment period, the process of revising the Common Rule appears to be in its final stages. However, transparency around the last steps in this process is critical. Over 2,000 comment submissions were received online and in hard copy, and it is currently unclear how the views of the public will be weighed and incorporated into the final revised policy – no doubt a daunting task. NCAI’s comments along with the comments of other tribal entities will be included in this process, but it is unlikely the views expressed in these submissions will ever achieve the “majority” status cited as a reason for incorporating some of the proposed revisions in the first place. It will be essential to ground the final revisions in the principles of research ethics, no matter the quantity of comments submitted in favor or against any particular change.

Nonetheless, there are some signals of hope that engagement with tribes and incorporation of tribal perspectives will continue to be pursued. Following an invitation shared during the Tribal Consultation conference call, Dr. Jerry Menikoff provided a second presentation of the proposed Common Rule revisions to tribal leaders at an annual NCAI event in February 2016. Additionally, OHRP has expressed interest in continuing to receive comments on the NPRM from tribes despite the closing of the formal public comment period.

Next Steps

As NCAI continues to pursue opportunities to engage with federal policymakers on the Common Rule revisions, lessons emerging from the NPRM revision process and content have already begun to have a role in other tribal-federal engagements. One clear example relates to the work of the NIH Tribal Consultation Advisory Committee (TCAC) formed in early September 2015 to provide “a forum for meetings between elected Tribal officials (or their designated representatives) and NIH officials to exchange views, share information, and seek advice concerning intergovernmental responsibilities related to the implementation and administration of NIH programs.” The TCAC grew from NIH’s Tribal Consultation Policy released in 2013, and while there was no primary focus on revisions to the Common Rule, the NPRM comment period overlapped with the group’s initial meetings and the NPRM was raised at several points.

At the second in-person TCAC meeting in late February 2016, the TCAC decided an essential early priority would be defining meaningful tribal consultation relative to other types of meetings (e.g., listening sessions, etc.) and advisory roles for NIH. The group is also working with NIH to identify areas that may benefit from special outreach to tribal nations and AI/AN citizens, as well as researchers working in tribal communities. Examples of activities already discussed include the explicit mention of tribal entities in requests for proposals, as well as the development of new requests for proposals that are specific to tribal research priorities and interests. While the NIH TCAC remains in its early stages, it’s possible the consultation processes defined by the group and the mechanisms identified for meeting the needs of tribal nations could become an important model for other federal agencies.

References


Increasing Diversity in the Health Professions: Reflections on Student Pipeline Programs

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Abstract

Despite major advances and technological improvements in public health and medicine, health disparities persist by race and ethnicity, income and educational attainment, and in some cases are increasing (Jackson & Garcia, 2014). These health disparities among these populations have even worsened or remained about the same since the landmark 1985 Report of the Secretary’s Task Force on Black & Minority Health released by then Secretary Margaret M. Heckler. Ensuring diverse public health and healthcare workforces to provide services to diverse populations, in combination with other strategies, can increase access to and quality of healthcare for vulnerable populations and decrease healthcare disparities. One mechanism for achieving a diverse public health and healthcare workforce is to establish, promote, and conduct student training programs in public health. The Office of Minority Health and Health Equity, Centers for Disease Control and Prevention (CDC), has partnered with institutions, colleges, universities, foundations, national organizations and associations to form and implement student training programs. This paper highlights a session “Public Health Professions Enhancement Programs” that was held during the 2015 symposium titled “National Negro Health Week to National Minority Health Month: 100 Years of Moving Public Health Forward” in Atlanta, Georgia. Presenters at the symposium consisted of interns and fellows who had participated in student programs in the Office of Minority Health and Health Equity at the CDC.

Keywords: Student Training Programs, Internship Programs, Fellowship Programs, Diversity, Health Equity, Disparities

Introduction

National data indicate that compared with the general population, racial and ethnic minority, low-income, and limited educational attainment populations have poorer health outcomes from several preventable and treatable diseases (CDC, 2013; CDC, 2011; NHQ & Disparities Report, 2015). Differences in access to healthcare, quality of care, and health measures, including life expectancy and infant mortality, have all been documented among racial and ethnic minority populations (Jackson & Garcia, 2014). In 2013, the leading causes of death in the United States were 1) heart disease; 2) cancer; 3) chronic lower respiratory disease; 4) accidents (unintentional injuries); 5) stroke (cerebrovascular diseases); 6) Alzheimer’s disease; 7) diabetes; 8) influenza and pneumonia; 9) nephritis, nephrotic syndrome, and nephrosis, and 10) intentional self-harm (suicide), which varied by race/ethnicity (Chang, Moonesinghe, Athar, Truman, 2015). Despite decades of technological advances in science and medicine, racial and ethnic minority populations are still experiencing disparities among most health status indicators. For some indicators and measures, the gaps in disparities are growing larger instead of becoming smaller (Artiga, Damico, Garfield, 2015).

In addition to racial and ethnic, low-income, and limited educational attainment populations, other characteristics make specific populations more vulnerable to health disparities, such as age, geographic location, language, gender, disability status, citizenship status and sexual identity and orientation (Jackson & Garcia, 2014). Responding to the persistent burden of racial and ethnic health disparities has been a federal priority since the release of the 1985 Secretary’s Task Force Report on Black and Minority Health (Heckler, 1985). This landmark report provided several recommendations about strategies for improving minority health, including attention to the demographic makeup of the public health and healthcare workforces.

More recently, The Kelly Report reiterated the need for a diverse health workforce in her re-examination of racial and ethnic health disparities in the United States (Black Caucus Health Braintrust, 2015). The Kelly Report reinforces the need for diverse public health and healthcare workforce training programs that support improved public health and healthcare systems, by increasing opportunities for minority patients to be served by healthcare practitioners and public health professionals with whom they share a common race, ethnicity, culture or language (USDHHS, 2001).

Although the healthcare workforce is enumerated and defined, the public health workforce is only now being better defined and understood. Tison and Gebbie in 2004 defined the public health workforce as being composed of “those who work for official public health agencies at all levels of government, community-based, and voluntary organizations with a health promotion focus, the public health-related staff of hospitals and healthcare systems, and a range of others in private industry, government, and the voluntary sector.” While the healthcare workforce includes those who were “in instructional programs that prepare individuals to practice as licensed professionals and assistants in the healthcare professions, related clinical sciences, and administrative and support services” (U.S. Department of Education, 2010).

The increasing predictions of the multiculturalism or the magnitude of diversity of the U.S. population culminating in a “majority-minority” country by the middle of the 21st century, bring more of a demand to increase the diversity of health professionals in public health and healthcare (Jackson & Garcia, 2014). Given the changing demographics of the United States, and its increasing cultural and linguistic diversity, HHS released the first version of the National Standards for Culturally and Linguistically Appropriate Services in Health and Healthcare (CLAS) in 2000, and enhanced these standards in 2010 (U.S. Department of Health and Human Services, 2010). These enhanced standards “aim to improve healthcare quality and advance health equity” by establishing the delivery of respectful and effective services by health organizations in serving the nation’s increasingly diverse populations (U.S. Department of Health and Human Services, 2001).

It is predicted that by 2020 there will be a shortage of public health professionals throughout the nation as “almost 110,000 workers were eligible to retire by 2012” and more are retiring every year (Johnson, 2008). As current population trends in the United States continue, the public health and healthcare workforces are facing a shortage of diverse public health workers and clinicians, leaving communities vulnerable to pending public health threats, infectious diseases, bioterrorism and other disasters (Association of American Medical Colleges, 2015; Johnson, 2008). Training programs for underrepresented minority populations in public health and healthcare are needed to help decrease and eliminate disparities in the United States (McClamrock & Montgomery, 2009).

Public health is concerned with protecting the health, safety, and welfare of the public, yet public health state, local and federal agencies are experiencing great losses in the workforce because of budget cuts and recruitment issues. The lack of public health training and limited public health training for public health employees is also a major concern for public health officials (Drehobl, Stover, Koo, 2014).

The case for diversity training and internship programs has been made as far back as 2004 with the publication of In the Nation’s Compelling Interest: Ensuring Diversity in the Health
Care Workforce by the Institute of Medicine (Institute of Medicine, 2004). This report discussed the under-representation of Blacks (African Americans), Hispanics and Native Americans within the healthcare professions, and provided a number of recommendations for healthcare profession and educational institutions. Among other suggestions, it called for public–private collaborations to support the development of a more diverse healthcare workforce.

Also in 2004, the Sullivan Commission on Diversity in the Health Care Workforce published Missing Persons: Minorities in the Health Professions (The Sullivan Commission, 2004). The Commission, named after former Secretary of Health and Human Services, Louis W. Sullivan, M.D., made systems and policy recommendations to address the small numbers of minorities in the healthcare professions. The Commission noted that increasing the diversity of healthcare providers would enhance culturally competent care and improve the health outcomes of minority populations. Similar to the IOM report, this report provided multiple recommendations for increasing minority students’ access to the educational pipeline to healthcare careers. The report emphasizes the need for leadership, commitment, and accountability in institutions of learning and in national professional organizations, and called for legislative options and a presidential task force to give urgency and focus to the problem (The Sullivan Commission, 2004; AAMC, 2015).

As the nation is becoming more diverse, the Association of American Medical Colleges (AAMC) produced a report to determine why applicants for medical schools had increased for all races with the exception of African American males, even though pipeline programs have been established to increase diversity. In this report, the AAMC mentioned two promising programs for minority youth interested in medicine. Those programs are (1) an inaugural class at Howard University called “Young Doctors DC” which is a peer-mentoring program designed to expose young black men to educational and career opportunities (AAMC, 2015) and (2) Minority Men in Medicine (MMM) at the University of North Carolina (UNC) which is designed as a mentoring program for minority males interested in medical and dental schools (AAMC, 2015).

More recent reports from the U.S. Department of Health and Human Services have further emphasized the importance of a diverse health workforce. Goal II of the IHS Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Health Care is to “strengthen the nation’s health and human services infrastructure and workforce” (USDHHS, 2011). One mechanism the action plan identifies is to “create a pipeline program for students to increase racial and ethnic diversity in the public health and biomedical sciences professions” (USDHHS, 2011). The other report, The National Partnership for Action to End Health Disparities (NPA), includes among its strategies, increasing “diversity and competency of the health workforce and related industry workforces through recruitment, retention, and training of racially, ethnically, and culturally diverse individuals, and through leadership action by healthcare organizations and systems” (OASH, 2011). Other plans and initiatives have been put in place at federal, state and local levels to increase diversity in the public health and health professions workforce (OASH, 2011). Training and internship programs for minority populations are widely utilized and are important mechanisms to create a diverse workforce among public health and healthcare professions (McClamrock & Montgomery, 2009; Smedley, Butler, Bristow, 2004).

Student pipeline and internship programs that enhance recruitment of underrepresented minorities can increase the likelihood of achieving a diverse workforce (Duffus, Trawick, Moonesinghe, Tola, Truman, Dean, 2014), and there are opportunities to create these programs in many locations where the right stakeholders and resources are present. This paper highlights past and present training programs at the CDC, sponsored by the OMHHE, as examples of efforts to increase the diversity of the nation’s workforce in public health and the healthcare professions in an effort to decrease and eliminate health disparities. These training programs were discussed in the concurrent session “Public Health Professions Enhancement Programs” during the 2015 symposium titled “National Negro Health Week to National Minority Health Month: 100 Years of Moving Public Health Forward” in Atlanta, Georgia.

Student Training Programs Sponsored by CDC’s Office of Minority Health and Health Equity

From its inception, the Office of Minority Health and Health Equity (OMHHE) at the CDC has partnered with institutions, colleges, universities, foundations, national organizations and associations to create and implement student training and internship programs. Over the years, the OMHHE has supported and managed training, internship, and fellowship programs through cooperative agreements (Duffus, Trawick, Moonesinghe, Tola, Truman, Dean, 2014).

Currently, four institutions are partnering with the OMHHE to provide the CDC Undergraduate Public Health Scholars Program (CUPS); the Summer Public Health Scholars Program at Columbia University; the Maternal Child Health Careers/Research Initiatives for Student Enhancement-Undergraduate Program, the Dr. James A. Ferguson Emerging Infectious Diseases Graduate Fellowship Program and the Public Health Leadership and Learning Undergraduate Student Success Program all at the Kennedy Krieger Institute; Project IMHOTEP at Morehouse College; and the Future Public Health Leaders Program at the University of Michigan. The Dr. James A. Ferguson Emerging Infectious Diseases Graduate Fellowship Program and Project IMHOTEP are training and internship programs that have been supported by the OMHHE for more than 20 years and have been successful in encouraging undergraduate and graduate students to pursue careers in public health and the healthcare professions (CDC, 2015; Duffus, Trawick, Moonesinghe, Tola, Truman, Dean, 2014).

The Summer Public Health Scholars Program (SPHSP)

The SPHSP is a 10-week summer training program hosted by Columbia University for junior and senior undergraduates and recent baccalaureate students. The program begins with visits to the CDC and introductions to public health professionals working at the federal level. The summer experience provides an overall orientation to public health, leadership training, and work experience. Students also gain experience in presenting an oral presentation given at the end of their work experience and preparing a final paper (CDC, 2015).

Kennedy Krieger Institute (KKI) Programs

One program housed at the KKI is called the Maternal Child Health Careers/Research Initiative for Student Enhancement which is an Undergraduate Program (MCHC/
RISE-UP). This program is also a 10-week summer training program for junior and senior undergraduates and recent baccalaureate students. The program consists of a national consortium of institutions: Kennedy Krieger Institute; Maryland Center for Developmental Disabilities; Johns Hopkins University School of Medicine, Nursing, and Public Health; University of Southern California, California State University – LA; and the University of South Dakota - Sanford School of Medicine for Disabilities. Students are trained in clinical practice, research, or community engagement and advocacy (CDC, 2015).

Dr. James A. Ferguson Emerging Infectious Diseases Graduate Fellowship Program (Ferguson Fellows)

The Ferguson Fellows Program, another program hosted by the Kennedy Krieger Institute (KKI), in nine weeks a research experience is provided for full-time medical, dental, pharmacy, veterinary, or public health graduate students interested in infectious diseases and health disparities research. These students present their work at the end of the program and are encouraged to submit their research for presentation at national meetings and for publication in peer-reviewed journals. The program is named after one of its founders, Dr. James A. Ferguson, Dean, School of Veterinary Medicine at Tuskegee University (CDC, 2015).

The Public Health Leadership and Learning Undergraduate Student Success (PLUSS) Program

The PLUSS Program, also hosted by the KKI, is an 8-week summer public health leadership and research program that provides 150 hours of student support during the academic year. The PLUSS Program is for undergraduate sophomore and junior students minoring or majoring in public health. The PLUSS program is conducted at several collaborative research sites: Kennedy Krieger Institute and Johns Hopkins Medical Institutions, University of Cincinnati, the National Institute for Occupational Safety and Health, and California State University – Los Angeles. PLUSS students participate in public health research, educational opportunities pertaining to health disparities and urban health issues, professional development, and community health promotion activities. Students are encouraged to submit research papers to national meetings and produce peer-reviewed publications. Students receive mentorship to help them gain acceptance to complete graduate professional programs in schools of public health (CDC, 2015).

Project IMHOTEP

The IMHOTEP internship at Morehouse College is a 11-week summer program designed for undergraduate junior and senior students and recent baccalaureate students. The internship was designed to increase the knowledge and skills of underrepresented students in public health and to promote the quality and quantity of well-trained professionals in the public health workforce. During the internship, students are engaged in a public health curriculum, enrichment activities, training, and mentoring. At the conclusion of the program, these interns deliver oral presentations, poster presentations, and a written manuscript suitable for publication in a scientific journal (CDC, 2015).

The Future Public Health Leaders Program (FPFLP)

The FPFLP at the University of Michigan is a 10-week summer program designed for undergraduate junior and senior students and recent baccalaureate degree students. These students participate in seminars, workshops, and community-based research activities. Also, these students receive leadership training, orientation to public health, real-world work experience, and tour the CDC (CDC, 2015).

Additional Training Programs in the OMHHE

For many years, the CDC-OMHHE sponsored a cooperative agreement with the Hispanic-Serving Health Professions Schools to implement the Hispanic-Serving Health Professions Schools - Graduate Fellowship Training Program (GFTP). Now the OMHHE has a Memorandum of Understanding with the Hispanic Serving Health Professions Schools to mentor some of its fellows in the fellowship program. The fellowship provides training opportunities for graduate, doctoral students, and recent college graduates who are interested in Hispanic health research within government agencies (CDC, 2015).

The OMHHE also partners with the CDC-Tuskegee Public Health Ethics Internship Program (for Undergraduates) based in Atlanta, Georgia, and the CDC-Tuskegee Public Health Ethics Fellowship Program (MPH students) based in Tuskegee, Alabama. These programs are jointly coordinated by the CDC’s Public Health Ethics Unit, Office of Scientific Integrity, Office of the Associate Director for Science in the Office of the Director and the Office of Health Equity, Division of STD Prevention, National Center for HIV/STD Prevention, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis and the Tuskegee University’s National Center for Bioethics in Research and Health Care at Tuskegee, Alabama (CDC, 2015).

Student Feedback from Recent Training Programs

Informal feedback was gathered from students and interns who have participated in the OMHHE student programs. These are among the responses of several students:

“After completing a summer fellowship with OMHHE’s Program for Undergraduate Researchers in Environmental Health (PURUSH), I was recommended for an ORISE position as a communications specialist. During that time, I worked as a health communicator on high visibility projects such as the Surgeon General’s Call to Action to Prevent Skin Cancer and the Melanoma Vital Signs…. I encourage other students to consider student, fellowship and internship programs as an opportunity to learn firsthand what CDC has to offer and to ultimately decide if it’s the type of career they would like to pursue.”

“The summer program was an amazing opportunity that provided me with my first professional experience in the field of public health. The first two weeks were difficult, but provided the foundation that would help me to understand some of my tasks in the coming months, such as preparing literature reviews, writing manuscripts, performing data analyses using SAS, and interpreting data. I enjoyed meeting people from diverse backgrounds and making lasting friendships.”

Project IMHOTEP
“I gained mentors, friends, experiences that I have kept until this day. It helped to shape my understanding of the CDC and see firsthand the programs that had been created to help form future public health leaders. It showed me another side of public health. I believe that including other types of agencies in the program would be beneficial for all involved, such as nonprofits, community based organizations, and other non-federal agencies.”

These comments from participating students reflect their enthusiasm about entering the field of public health.

**CDC’S Long-Standing Commitment to Training Programs**

In addition to the training programs mentioned, other examples of student programs previously administered by OMHHE and supported by Centers, Institutes, and Offices (CIOs) at the CDC include 1) The Annual Symposium on Career Opportunities in Biomedical Sciences and Health Professions; 2) The Starlab Middle School Pipeline Science Summer Program; 3) The Public Health Summer Fellowship Program; 4) Increasing Minority Populations in Public Health; 5) The Environmental Medicine Rotation Program; 6) The Master of Public Health Program at Morehouse School of Medicine; and 7) The Regional Research Center for Minority Health (RRCMH) (CDC, 2011). The OMHHE as well as other CIOs throughout the CDC were instrumental in helping to start and fund the Master of Public Health Program at Morehouse School of Medicine (CDC, 2011).

These student training programs introduced historically-underrepresented minority students to the field of public health and career choices in more clinically-oriented health professions (such as medicine, dentistry, pharmacy, nursing, etc.). Most of the programs were established to provide research, public health practice and theory, and evaluation experience to students interested in pursuing careers in public health or medicine. Students interacted with public health researchers, top level officials, public health practitioners, and public health partners.

**Feedback from Previous Students Now Public Health Professionals**

Feedback was received from two previous students of CDC’s student programs who are now public health professionals. The responses from these previous students are as follows:

“The overall program had a tremendous impact on my current career. It inspired and encouraged me to pursue education beyond the Master’s degree level and complete a Ph.D. degree. I teach leadership and healthcare research methods classes at the undergraduate and graduate college levels. Credit for the majority of the early skills that were acquired in research and administration goes to my internship program.”

“Being involved in the student program helped me to realize that I needed to pursue graduate education and become a public health practitioner. The program helped me realize how public health is needed in the United States and very much needed by minority populations. I am now working in public health to give back to the community in which I came from and to make a difference in the health of minority populations.”

**Recruitment of Underrepresented Populations**

A review by the U.S. Bureau of Health Professions identified several advantages to recruiting health professionals from underrepresented minority groups (USDHHS, 2001): 1) these professionals disproportionately serve minority populations, 2) minority patients tend to receive better care from providers who are demographically similar or of the same racial and ethnic background, and 3) persons for whom English is a second language, or if they don’t speak English, communicate better with providers who speak their primary language, and they are more likely to keep follow-up appointments when treated by professionals who speak the same language. In addition, medical and public health professionals from underrepresented groups are likely to serve in poor or rural communities (Williams, Hansen, Smithey, Burney, Koplitz, Koyajma, ... Bakos, 2014).

Thus, increasing the racial and ethnic diversity of the public health and healthcare workforce is essential for the adequate provision of culturally competent care to our nation’s increasing racial and ethnic minority and other vulnerable populations (Cohen, Gabriel, Terrell, 2002; Rosenstock, Silver, Helsing, Evashwick, Katz, Kominski, ... Sumaya, 2008; Betancourt, Green, Carrillo, Park, 2005; Grumback & Mendoza, 2008). For example, in 2014, the projected United States population was 318,857,056 people. Of that number, Black or African Americans represented 13.2% of the population; American Indians and Alaska Natives 1.2%; Asians 5.4%; Native Hawaiians and Other Pacific Islanders 0.2%; persons of two or more races 2.5%; and Hispanic or Latinos 17.4% (US Census Bureau, 2015).

In fact, one of the early initiatives of the CDC, Office of Minority Health and Health Equity after its establishment in 1988 was the implementation of the public health student pipeline programs to increase the diversity of the public health and healthcare workforces. The CDC established the Office of Minority Health and Health Equity, then called the Office of the Associate Director for Minority Health in response to the Heckler Report. The available literature suggests that “more underrepresented populations need to be trained in public health and healthcare” such as certain racial and ethnic minority populations (Institute of Medicine, 2004).

Identifying the best evidence-based public health and healthcare training practices and the education integration of social and public health training programs is critical for achieving health equity (Spencer, Schooley, Anderson, Kochtitzky, DeGroff, Devlink, Mercer, 2013). There are many challenges facing the health professions workforce. A diverse public health and healthcare workforce is necessary for improving the health status of Americans and in decreasing and eliminating disparities (Cohen, Gabriel, Terrell, 2002).
Conclusion

As demographics of the U.S. population become more diverse with many different cultures, backgrounds, and languages, there is more of a demand to increase the diversity of the public health and healthcare workforces. There is a great need for more intentional efforts to recruit public health and healthcare professionals from populations most adversely affected by health disparities. Broad recruiting strategies that reach the general population are necessary, but not sufficient to accomplish this purpose (The National Academies Press, 2003). This article highlights the CDC’s longstanding commitment to student training programs for certain underrepresented populations such as racial and ethnic minority and low-income populations. According to statements from a few of the former students in the CDC student training programs, these programs have been successful in encouraging students to pursue careers in public health. Pipeline programs such as these at the CDC are critical for introducing racial and ethnic minority and low-income students to the fields of public health and healthcare. More evaluations should be conducted to determine the impact of these student training pipeline programs.

Student programs that enhance recruitment of underrepresented populations, in combination with other strategies, can increase access to and quality of healthcare for vulnerable populations and decrease healthcare disparities (The National Academies Press, 2003). There are opportunities to create these programs in many locations where the right stakeholders and resources are present (The National Academies Press, 2003). Current training programs are using innovative and creative designs for increasing the investment of student pipeline programs for public health and healthcare. These programs require early interventions and can be coupled with more innovative and creative designs, making opportunities more sustainable over the long term (The National Academies Press, 2003).

References


Predictors of Self-Reported Mammography Screening Among Women Aged 18 Years and Over in the United States: Findings from the 2012 Behavioral Risk Factor Surveillance System (BRFSS)

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Abstract
Regular mammography screening can reduce the risk of death from breast cancer for women in the United States (U.S.). The objective of this study was to assess the factors associated with self-reported mammography screening among females aged 18 years and over in the U.S. The data used for this study were obtained from the 2012 Behavioral Risk Factors Surveillance System (BRFSS). A multivariable logistic regression model was used to estimate adjusted odd ratios (AORs) and 95% confidence intervals (CIs) for factors associated with self-reported mammography screening. Analyses were conducted using Statistical Analysis System (SAS) version 9.3. The results of the study indicate that Non-Hispanic Whites (AOR 0.60, 95% CI: 0.57-0.63), Hispanic or Latinos (AOR 0.68, 95% CI: 0.63-0.73), Asians (AOR 0.42, 95% CI: 0.36-0.50), Native Hawaiian or Other Pacific Islanders (AOR 0.54, 95% CI: 0.35-0.83), and American Indian or Alaska Natives (AOR 0.80, 95% CI: 0.70-0.90) were less likely to report mammography screening when compared to African Americans. Living in the Midwest (AOR 0.91, 95% CI: 0.87-0.95) and West regions (AOR 0.77, 95% CI: 0.74-0.84) also decreased
the likelihood of reporting mammography screening compared to those living in the Southern region of the United States. Findings from this study suggest that socio-demographic factors and region of residence are predictors of self-reported mammography screening among females aged 18 years and over in the U.S.

**Keywords:** Mammography screening; females 18 years and over; BRFSS; United States

### Introduction

Breast cancer is the most common type of cancer and the second leading cause of death among women in the United States; it is exceeded only by some forms of skin cancer (American Cancer Society [ACS], 2015). According the ACS, approximately 231,840 new cases of invasive breast cancer will be diagnosed among women in the United States (ACS, 2015). Furthermore, it is estimated that 40,290 American women will die from the disease in 2015 (ACS, 2015). With staggering statistics such as these, measures to reduce mortality and morbidity rates of breast cancer have become a major health concern. Research has shown that the most effective method for decreasing death rates of breast cancer is for women to receive regular intervals of breast cancer screening (Mandelblatt et al., 2009; Smith, Brooks, Cokkinides, Saslow, & Brawley, 2013; Williams, Garvican, Tosteson, Goodman, & Onega, 2015).

A screening mammogram is an x-ray image of the breast that is used to detect breast cancer in women who have no symptoms (ACS, 2015). In the year 2015, it was reported that 66% of women 40 years of age and older received a mammogram in the past two years, a rate lower than what was projected by the Healthy People 2020 target (ACS, 2015). Understanding the predictive factors associated with mammography screening patterns among women 18 years and over in the United States could aid in developing targeted interventions and health programs for groups of women who exhibit lower rates of screening.

### Methods

To identify factors associated with mammography screening among persons aged 18 years and over in the United States, this study analyzed 2012 data obtained from the Behavioral Risk Factor Surveillance System ([BRFSS]; N= 272,752). BRFSS is the nation’s premier system of health-related telephone surveys that collect state data annually from a random sample of U.S. adults aged 18 years and older regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, BRFSS now collects data in all 50 states, the District of Columbia, and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world. A clustering sample design was used to account for differences in the probability of selection and nonresponse in order to accurately derive U.S. and state-based population estimates. The annual surveys consist of a core set of questions that are asked in all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands. The mammography screening questions used for this study were constructed based one of the core questions used in the BRFSS (Centers for Disease Control and Prevention [CDC], 2012).

### Data Analysis

Univariate analyses were performed to describe the frequency and proportion of select characteristics (race and ethnicity, age, education, income, marital status, and region of residence). Bivariate analyses were conducted to assess the bivariate association between self-reported mammography screening and respondent characteristics. A multivariable logistic regression model was used to estimate adjusted odds ratios (aORs) and 95% confidence intervals (95% CI) for factors associated with self-reported mammography screening. All predictors of mammography with a p value of ≤ 0.05 in the bivariate variable analyses were entered into the multivariable logistic model. For the self-reported mammography screening model, the variables were race and ethnicity, age, education, income, marital status, and region of residence. Bivariate and multivariable analyses excluded persons with responses that were missing or recorded as "don't know/not sure" or "refused." A 2-sided p value <0.05 was considered to indicate statistically significant. Analyses were conducted using SAS version 9.2.
Results

The summary of the socio-demographic characteristics and select variables including region of residence for the 272,752 participants aged 18 years and over surveyed in the 2012 BRFSS are presented in Table 1. Of the 272,752 participants who responded to the question “Have you ever had a mammogram?” 216,850 (79%) reported receiving a mammogram, while 572,36 (21%) reported they did not receive a mammogram (Table 1). Of the 216,850 respondents who have received a mammogram, 44% were non-Hispanic white; and 47% were between 45-64 years. The majority (39%) of the respondents had a high school education or less; and 34% resided in the South region of the United States (Table 1).

Table 1. Number and Percentage of Respondents by Socio-Demographic Characteristics and Region of Residence, 2012 BRFSS, United States.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Had a Mammogram (n=272,752)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Total</td>
<td>216,850</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>95,553</td>
</tr>
<tr>
<td>Non-Hispanic Black (AA)</td>
<td>14,132</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>13,111</td>
</tr>
<tr>
<td>Asian</td>
<td>7,860</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>103.0</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>18,870</td>
</tr>
<tr>
<td>Two or more races</td>
<td>8,887.2</td>
</tr>
<tr>
<td>Don't know/Not sure</td>
<td>243.0</td>
</tr>
<tr>
<td>Other</td>
<td>779.0</td>
</tr>
<tr>
<td>Refused</td>
<td>1,383.0</td>
</tr>
<tr>
<td>Total</td>
<td>216,849.0</td>
</tr>
</tbody>
</table>

| Age Group                        |     |   |     |    |
| 18-44                            | 24,611  | 11.5 | 46,801 | 82.3 |
| 45-64                            | 10,001.0 | 46.7 | 6,016 | 10.6 |
| 65-74                            | 4,827.9 | 22.5 | 1,743 | 3.1 |
| 75 and above                      | 4,173.5 | 19.3 | 2,333 | 4.1 |
| Total                            | 21,428.0 | 100.0 | 56,893.0 | 100.0 |

| Level of Education               |     |   |     |    |
| High School or less              | 8,444.0 | 39.0 | 20,160 | 35.3 |
| Some College                     | 6,049.5 | 28.0 | 17,320 | 30.3 |
| College Graduate                 | 7,138.6 | 33.0 | 19,954 | 34.4 |
| Total                            | 21,632.1 | 100.0 | 57,134.0 | 100.0 |

When compared to non-Hispanic Blacks, non-Hispanic Whites (aOR 0.60, 95% CI: 0.57-0.63), Hispanic or Latino (aOR 0.68, 95% CI: 0.63-0.73), Asian (aOR 0.42, 95% CI: 0.36-0.50), Native Hawaiian or Other Pacific Islander (aOR 0.54, 95% CI: 0.35-0.83), and American Indian or Alaska Native (aOR 0.80, 95% CI: 0.70-0.90) were less likely to report mammography screening (Table 2). When compared to participants who were in the age group 18-44 years of age, those in the age group 45-64 years (AOR=2.92; 95% CI: 2.83-3.01), 65-74 years (AOR=5.38; 95% CI: 5.08-5.68) and 74 and above (AOR=40.01; 95% CI: 37.65-42.55) were more likely to report having had a mammogram. The research revealed similar patterns in levels of education and annual household incomes. Those participants with some college education (AOR= 1.10; 95% CI= 1.06, 1.13) and those who were college graduates (AOR= 1.18; 95% CI= 1.14, 1.22) had higher odds of getting a mammogram when compared...
to those with less than a high school education. Also, compared to participants with an annual household income of less than $24,999, those with an annual household income of $25,000-$49,999 also had a higher odds of getting a mammogram (AOR= 1.25; 95% CI=1.20, 1.30), as did those with an annual household income of $50,000 - $74,999 (AOR= 1.46; 95% CI=1.40, 1.53) and $75,000 or more (AOR= 1.88; 95% CI=1.80, 1.97).

Table 2. Multivariable Analysis of Factors Associated with Having Had a Mammogram, 2012 BRFSS, United States.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>HAD A MAMMOGRAM</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic Black (AA)</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>0.60 (0.57-0.63)</td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>0.68 (0.63-0.73)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>0.42 (0.36-0.50)</td>
<td></td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>0.54 (0.35-0.83)</td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>0.80 (0.70-0.90)</td>
<td></td>
</tr>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17-44</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>45-64</td>
<td>29.26 (28.30-30.25)</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>53.78 (50.80-56.98)</td>
<td></td>
</tr>
<tr>
<td>75 and above</td>
<td>40.01 (37.65-42.55)</td>
<td></td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School or less</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>1.10 (1.06-1.13)</td>
<td></td>
</tr>
<tr>
<td>College Graduate</td>
<td>1.18 (1.14-1.22)</td>
<td></td>
</tr>
<tr>
<td><strong>Annual Household Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $24,999</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>$25,000 to $49,999</td>
<td>1.25 (1.20-1.30)</td>
<td></td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>1.46 (1.40-1.55)</td>
<td></td>
</tr>
<tr>
<td>$75,000 or more</td>
<td>1.88 (1.80-1.97)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>1.81 (1.75-1.88)</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>2.20 (2.10-2.31)</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>1.93 (1.78-2.10)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1.73 (1.63-1.84)</td>
<td></td>
</tr>
</tbody>
</table>

When compared to never married participants, those who were married (AOR= 1.81; 95% CI= 1.75, 1.88) were more likely to get a mammogram, as were divorced (AOR= 2.20; 95% CI= 2.10, 2.31), separated (AOR= 1.93; 95% CI= 1.78, 2.10), and widowed participants (AOR= 1.73; 95% CI= 1.63, 1.84) (Table 2).

**Discussion**

The findings from this study reveal that 79% of women in the sample self-report to have ever had a mammogram. Even so, there are varying characteristics among the women who report to have had screening and those who have not. These differences included variances in race, age, marital and socioeconomic status, and region of residence.

According to our analysis, African American women have the highest rates of self-reported mammography screening, which is expected to decrease breast cancer mortality (Mandelblatt et al., 2009; Smith, Brooks, Cokkinides, Saslow, & Brawley, 2013; Williams, Garvican, Tosteson, Goodman, & Onega, 2015). However, African American women continue to have substantially higher rates of breast cancer morbidity rates compared to women of other races (Ademuyiwa et al., 2015; Bandera, Maskarinec, Romieu, & John, 2015; Kumar & Aggarwal, 2016; Rizzo, Sherman, & Arciero, 2015) as well as higher breast cancer mortality rates (Bandera et al., 2015; Kumar & Aggarwal, 2016). Thus, to reduce breast cancer mortality in African American women, other means beyond mammography screening must be considered. Women with the lowest rates of screening include Hispanic and American Indian/Alaskan Native women. As such, these populations may benefit most from targeted messages regarding the utility of mammography as a breast cancer screening tool.

The positive association between socioeconomic status and educational attainment with health is not an uncommon phenomenon in the fields of public health and medicine (Chen & Miller, 2013; Haught, Rose, & Brown, 2016; Randall, Martin, Bishop, Johnson, & Poon, 2012). Results from this study reveal a similar association; higher rates of screening were associated with higher annual income or higher level of education.
Our findings suggest that women under 45 years of age have the lowest rates of mammography screening. Of note, this same age group is known to have more aggressive forms of breast cancer (Berkey, Tamimi, Rosner, Frazier, & Colditz, 2012; Freedman & Partridge, 2013; Johnson-Turbes, Schluter, Moore, Buchanan, & Fairley, 2015; Mobley & Kuo, 2015), therefore targeted screenings in women 45 and younger may improve the outcomes of this age group.

Geographic disparities in diagnoses of breast cancer have been explored in the past, but the studies have been state specific, emphasized specific stages in breast cancer, or did not utilize the more recent data (Keller, Guilfoyle, & Sariego, 2011; Kuo, Mobley, & Anselin, 2011; Mobley & Kuo, 2015). Women living in the South Remainder, South Black Belt States and the Northeast regions were all more likely self-report having had a mammography test in contrast to women in the Western and Midwestern states. Efforts to increase mammography should target women who reside in those geographic areas with less screening.

Curiously, the results of this study show that there is a difference in marital status and uptake of mammogram screenings. Specifically, women who are divorced are more likely to self-report to have had a mammogram compared to women who have never been married and women who are married, widowed, or divorced. There is limited research that explores marital status and cancer screening behaviors therefore such relationships should be explored further.

Study Limitations and Strengths

A strength of this study is that it utilized the BRFSS, the largest continuously conducted health dataset available. Analyses included 272,752 female respondents that reported having had a mammography screening at least once in their lifetime. Limitations are those which are inherent to the analysis of survey data. There was the possibility of recall bias from the respondents. Also the BRFSS collects data only from non-institutionalized individuals who have a telephone.

Conclusion

This study provides data which can be used to predict populations least likely to get mammography screening, thereby allowing for targeted interventions. Findings from this study also reveal that efforts to reduce breast cancer mortality in African American women need to be expanded beyond mammography screening.

References


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### Determinants of Self-Reported Prostate-Specific Antigen (PSA) Testing Among Persons 18 years and over in the United States: Findings from the 2012 Behavioral Risk Factor Surveillance System (BRFSS)

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Abstract

Studies have shown that Prostate-specific antigen (PSA) testing can decrease the risk of death from prostate cancer for men 18 years of age and older living in the United States. Despite the proven preventative benefits of PSA testing, minorities participate in screening at disproportionately lower rates than their Caucasian counterparts (Hosain, Sanderson, Du, & Strom, 2012). The objective of this study was to identify and assess the determinants of self-reported PSA testing for the minority participant group. The data utilized in this study were obtained from the 2012 Behavioral Risk Factors Surveillance System (BRFSS). A multivariable logistic regression model was used to estimate adjusted odd ratios (AORs) and 95% confidence intervals (CIs) for factors associated with self-reported PSA testing. The analyses were conducted using the Statistical Analysis System (SAS) version 9.3. The results of the study revealed that African American men (aOR 1.23; 95% CI: 1.142-1.301) and those residing in the South Black Belt States (aOR 1.35, 95% CI: 1.295, 1.414) were more likely to have had PSA testing than the other minorities identified in the participant group. Hispanic or Latino (aOR 0.77, 95% CI: 0.723-0.822), Asian (aOR 0.48, 95% CI: 0.397-0.576), and American Indian and Alaska Native men (aOR 0.775 CI: 0.681-0.882) were less likely to have received prostate cancer screening. Men who are between the ages of 17-44, have a high school education or less, have an annual household income of less than $24,999, or reside in the Northeast region of the country were less likely to have had PSA testing. Ultimately, the socio-demographic factors and regions of residence identified in this study were predictors of self-reported PSA testing among men 18 years of age or older in the U.S.

Keywords: Prostate-specific Antigen (PSA) testing, males 18 years and over, BRFSS, United States

Introduction

Each year, an estimated 220,800 new cases of prostate cancer occur in the United States, making it the most commonly diagnosed cancer in men (Centers for Disease Control [CDC], 2014; American Cancer Society, 2015). The lifetime risk of diagnosis is currently estimated to be 15.9% (Pollack, Noronha, Green, Bhavsar, & Carter, 2012; CDC, 2014). However, men can reduce prostate cancer morbidity and mortality by taking preventative measures for early detection and screening or the Prostate-specific antigen (PSA) test. While PSA screening is an effective tool for reducing disease morbidity and mortality and increasing the quality of life for those diagnosed with prostate cancer, some men experience barriers to participation that resulted in low compliance rates (Ferrante, Shaw, & Scott, 2011). The objective of this study was to identify and assess the determining factors of self-reported PSA testing among men 18 years of age and older in the U.S.

Methods

The data used for this study were from the 2012 Behavioral Risk Factor Surveillance System (BRFSS) (n = 131,365), an ongoing, state-based, random-digit-dialed telephone survey of non-institutionalized adults aged 18 years and older who reside in the United States. BRFSS collects data on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. A clustering sample design was used to account for differences in the probability of selection and nonresponse in order to accurately attain U.S. and state-based population estimates. The annual surveys consist of a core set of questions that are asked in all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands.
Islands. The prostate cancer screening questions used for this study were formulated based on one of the core inquiries used in the BRFSS (CDC, 2012).

Measures

All measures in this study were based on the self-reported data obtained from the 2012 BRFSS.

PSA Testing

Self-reported PSA testing was defined by a participant’s answering “yes” to the question: “Have you ever had a PSA test?” Having had a PSA test represented the outcome variables with “Yes,” “No,” “Don’t know/not sure,” or “Refused” responses. Only those records with “yes” or “no” responses to the question were included in the analysis (records with “unknown” or “refused” responses or missing data were excluded from the analysis).

Demographic Characteristics

The demographic characteristics obtained from the 2012 BRFSS survey included the participants’ gender (male), race or ethnicity, age, education, income, employment status, perceived health status, and region of residence. Records with “do not know/not sure,” “unknown,” “refused,” and missing data responses were excluded from each of the demographic, socioeconomic, and geographic variables.

Data Analysis

The data were analyzed using univariate, bivariate, and multivariable statistics. Univariate statistics was used to develop a general description of the sample, bivariate analysis was used for testing individual influence of socio-demographic variables on self-reported PSA testing, and a multivariable logistic regression model was used to estimate adjusted odds ratios (ORs) and 95% confidence intervals (95% CI) for determinants of self-reported PSA testing. All determinants of PSA testing with a p value of ≤0.05 in the bivariate variable analyses were entered into the multivariable logistic model. These variables include race/ethnicity, age, education, income, employment status, region of residence, and perceived health status. Bivariate and multivariable analyses excluded persons with responses that were missing or recorded as “don’t know/not sure” or “refused.” A 2-sided p value <0.05 was considered to indicate results that were statistically significant. All analyses were conducted using SAS version 9.2.

Results

The summary of the socio-demographic characteristics for the 131,365 men aged 18 years and over surveyed in the 2012 BRFSS are presented in Table 1. Of the 131,365 participants who responded to the question: “Have you had a PSA test?” 83,812 (64%) reported having had a PSA test, and 47,553 (36%) reported not having had screening. Of the 83,812 respondents who had a PSA test, 82% were White, 48% were between 45-64 years of age, 43% were college graduates, 68% were retired, 30% were from the South region of the United States, 35% had an annual household income of $75,000 or more, and 79% perceived their health status as poor (Table 1).

Table 1. Number* and Percentage of Respondents who reported Having Had a PSA Test by Select Characteristics: 2012 BRFSS, United States.

<table>
<thead>
<tr>
<th>Select Characteristics</th>
<th>HAD PSA TEST (N=131,365)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes n (%)</td>
</tr>
<tr>
<td>Overall</td>
<td>83,812 (63.8)</td>
</tr>
<tr>
<td>Race/Ethnicity (n=131,365)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>37,972 (82.0)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>3,682 (8.0)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>3,792 (8.2)</td>
</tr>
<tr>
<td>Asian</td>
<td>279 (0.6)</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>593 (1.2)</td>
</tr>
<tr>
<td>Age Group (n=131,365)</td>
<td></td>
</tr>
<tr>
<td>18-44</td>
<td>2,396 (2.9)</td>
</tr>
<tr>
<td>45-64</td>
<td>40,105 (47.9)</td>
</tr>
<tr>
<td>65-74</td>
<td>24,717 (29.4)</td>
</tr>
<tr>
<td>75 and above</td>
<td>16,594 (19.8)</td>
</tr>
<tr>
<td>Level of Education (n=131,921)</td>
<td></td>
</tr>
<tr>
<td>High School or less</td>
<td>27,492 (32.7)</td>
</tr>
<tr>
<td>Some College</td>
<td>20,494 (24.3)</td>
</tr>
<tr>
<td>College Graduate</td>
<td>36,154 (43.0)</td>
</tr>
<tr>
<td>Level of Income (n=119,742)</td>
<td></td>
</tr>
<tr>
<td>Less than $24,999</td>
<td>15,542 (20.4)</td>
</tr>
<tr>
<td>$25,000 to $49,999</td>
<td>20,727 (27.2)</td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>13,454 (17.6)</td>
</tr>
<tr>
<td>$75,000 or more</td>
<td>26,531 (34.8)</td>
</tr>
<tr>
<td>Perceived Health Status (n=131,727)</td>
<td></td>
</tr>
<tr>
<td>Poor Health</td>
<td>66,408 (79.0)</td>
</tr>
<tr>
<td>Good Health</td>
<td>17,613 (21.0)</td>
</tr>
</tbody>
</table>
The results of the multivariable analysis are presented in Table 2. The factors associated with decreased likelihood of self-reported PSA testing include being American Indian or Alaskan Native (AOR = 0.77; 95% CI = 0.68, 0.88), Asian (AOR = 0.48; 95% CI = 0.40, 0.58), Hispanic or Latino (AOR = 0.77; 95% CI = 0.68, 0.88), or homemakers (AOR = 0.56; 95% CI = 0.42, 0.74). When compared to Caucasians, African Americans were more likely to report having had PSA testing (AOR = 1.21; 95% CI = 1.42, 1.30). Participants who were 45–64 years of age (AOR = 5.91; 95% CI = 5.61, 6.21), 65–74 years of age (AOR = 15.24; 95% CI = 14.32, 16.22), and 75 years of age and above (AOR = 15.12; 95% CI = 14.10, 16.22) were more likely to report having had a PSA test than those men between 18–44 years of age. Participants with some college education (AOR = 1.42; 95% CI = 1.37, 1.47) and those who were college graduates (AOR = 1.76; 95% CI = 1.70, 1.82) had a higher probability of having had a PSA test than those with less than a high school education (Table 2).

**Table 2.** Number* and Percentage of Respondents who reported Having Had a PSA Test by Select Characteristics: 2012 BRFSS, United States.

<table>
<thead>
<tr>
<th>Select Characteristics</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment Status (n=131,851)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed for wages</td>
<td>27,595 (32.8)</td>
<td>23,865 (50.0)</td>
</tr>
<tr>
<td>Unable to work</td>
<td>5,331 (6.3)</td>
<td>4,625 (9.7)</td>
</tr>
<tr>
<td>Out of work for less than a year</td>
<td>1,159 (1.4)</td>
<td>1,585 (3.3)</td>
</tr>
<tr>
<td>Out of work for more than a year</td>
<td>1,746 (2.1)</td>
<td>2,148 (4.5)</td>
</tr>
<tr>
<td>Student</td>
<td>117 (0.1)</td>
<td>177 (0.4)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>102 (0.1)</td>
<td>186 (0.4)</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>9,650 (11.5)</td>
<td>6,624 (13.9)</td>
</tr>
<tr>
<td>Retired</td>
<td>38,424 (45.7)</td>
<td>8,518 (17.8)</td>
</tr>
</tbody>
</table>

**Region of Residence (n=130,497)**

<table>
<thead>
<tr>
<th>Region of Residence</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Black Belt States</td>
<td>16,499 (19.9)</td>
<td>7,985 (16.8)</td>
</tr>
<tr>
<td>Remainder</td>
<td>8,345 (10.1)</td>
<td>4,407 (9.3)</td>
</tr>
<tr>
<td>Midwest</td>
<td>20,188 (24.3)</td>
<td>11,696 (24.6)</td>
</tr>
<tr>
<td>Northeast</td>
<td>17,751 (21.4)</td>
<td>11,189 (23.6)</td>
</tr>
<tr>
<td>West</td>
<td>20,233 (24.3)</td>
<td>12,204 (25.7)</td>
</tr>
</tbody>
</table>

**Level of Education**

<table>
<thead>
<tr>
<th>Education</th>
<th>Ref.</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School or Less</td>
<td>1.42</td>
<td>(1.37–1.47)</td>
</tr>
<tr>
<td>Some College</td>
<td>1.76</td>
<td>(1.70–1.82)</td>
</tr>
</tbody>
</table>

**Perceived Health Status**

<table>
<thead>
<tr>
<th>Health Status</th>
<th>Ref.</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good Health</td>
<td>1.03</td>
<td>(1.00–1.07)</td>
</tr>
<tr>
<td>Poor Health</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Level of Income**

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Ref.</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $24,999</td>
<td>1.83</td>
<td>(1.76–1.91)</td>
</tr>
<tr>
<td>$25,000 to $49,999</td>
<td>2.31</td>
<td>(2.21–2.43)</td>
</tr>
<tr>
<td>$75,000 or more</td>
<td>2.77</td>
<td>(2.65–2.90)</td>
</tr>
</tbody>
</table>

**Employment Status**

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Ref.</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed for wage</td>
<td>1.65</td>
<td>(1.56–1.75)</td>
</tr>
<tr>
<td>Unable to work</td>
<td>0.99</td>
<td>(0.59–0.68)</td>
</tr>
<tr>
<td>Out of work for less than a year</td>
<td>1.10</td>
<td>(1.02 – 1.19)</td>
</tr>
<tr>
<td>Student</td>
<td>1.02</td>
<td>(0.78 – 1.34)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>0.56</td>
<td>(0.42 – 0.74)</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>1.10</td>
<td>(1.06 – 1.15)</td>
</tr>
<tr>
<td>Retired</td>
<td>1.65</td>
<td>(1.56 – 1.75)</td>
</tr>
</tbody>
</table>
The results regarding level of education and income differences in PSA testing were largely consistent with prior studies (Obana & O’Lawrence, 2015; Tataw, 2012; Weinrich, Reynolds, Tingen, & Starr, 2000; Weinrich, Weinrich, Priest, & Fodi, 2003). Presumably, men with higher salaries are more likely to have health insurance coverage or other means by which to pay for PSA testing. Not surprisingly, when looking at the utility of free prostate cancer screening, men with higher incomes ($25,021 or more) were significantly less likely to participate than men with incomes in the referent range ($9,601-$25,020) (Weinrich, et al, 2003).

The existing research regarding the relationship between employment status and self-reported PSA testing is limited. Our results indicate that men who were self-employed, unable to work, or retired were more likely to report having had a PSA test. Unemployed respondents were more likely to have had a PSA test (So et al, 2014). A likely explanation is that scheduling flexibility for men who are self-employed, unable to work, and retired may increase their ability to participate in screening. Based on the findings in this study, men who resided in the South Black Belt States and Southern Remainder regions were more likely to report having had a PSA screening when compared to those living in the Midwest and West regions of the country. Similarly, research indicates that men living in urban areas and in states with a lower prevalence of physicians have a lesser chance of participating in prostate cancer screening (Garg, Raisch, Selig, & Thompson, 2013).

**Study Limitations and Strengths**

The major strength of this study is the use of the BRFSS data that employed a sample representative of the national population, as the BRFSS is the largest representative dataset in the U.S. Although the use of the BRFSS substantiates the validity of this study, there were some limitations in utilizing the database. The BRFSS data is not generalizable to the entire United States population. The survey did not include institutionalized populations representing men living in long-term care facilities, on naval bases, or other institutions. It relies on landline telephone interviews for data collection and excludes individuals without telephone service, resulting in potential response bias. Finally, BRFSS data are self-reported, which can affect the reliability and validity of the survey through recall bias.

**Conclusion**

The findings show that socio-demographics and region of residence were key determinants of PSA testing among 2012 BRFSS survey participants. These findings can be used to tailor interventions aimed at increasing prostate screening among those least likely to get screened.
References


The Affordable Care Act: Challenges and Leadership Opportunities

Kevin B. Williams, Ph.D., MPH
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Abstract
Dr. Bailus Walker’s address highlighted historical and contemporary challenges that people of color, face, and particularly the challenges persons of African decent, have continued to encounter in the United States and around the world. The central themes of his keynote were good guiding posts to the very real shared responsibility that everyone has to make certain, each person is making continuous contributions to ensure conditions in which the individual and the public’s health can be protected and thrive. This researcher chose to focus specifically, to Dr. Walker’s written comments in his Keynote address in which he stated, “even to the most casual observer of developments in science and in public health, it is evident that the responsibilities of public health continue to broaden.” The agenda is much longer now than in previous decades.” The researcher briefly addressed in this response some of the challenges and leadership opportunities in public health available through the passage of The Affordable Care Act. The importance of leadership, policy engagement and social marketing for those that practice public health advocacy is highlighted in this response as it relates to The Affordable Care Act.

Keywords: Leadership, Policy, Social Marketing

Introduction
On March 23, 2010 in the East room of the White House President Barack Obama signed The Affordable Care Act (ACA) which is often politically referred to as Obamacare. Andrewlust and Siddiqui (2011), highlighted that one of the central goals of the act is achieving health equity. Health equity is centered on the elimination of potentially avoidable differences or disparities in health between socially advantaged and disadvantaged groups of people (Adrewlust and Siddiqui, 2011, p. 1830). One of the biggest challenges for the execution of the Affordable Care Act has been significant legal encounters that opponents of the act have mounted throughout the policy process. For example, on the official website for The United States Department of Justice, a section is titled “Defending the Affordable Care Act” which indicated the law has become the subject of several lawsuits challenging the constitutionality of parts of the act. “The Department is vigorously defending the law in these cases” (The United Department of Justice, 2014 par. 1). On March 4, 2015 the Supreme Court justices heard another legal challenge to the Affordable Care Act, King V. Burwell, which deals with subsidies for health insurance. In June of 2015 the Supreme Court upheld the Obamacare subsidies.

For health care professionals, consumers and the general public, the amount of challenges to this particular health reform can appear to be overwhelming. What do we do as a community, professional and academic leaders in such a hyper intensive environment regarding this policy? As public health professionals and or community public health leaders, we are charged with engaging in the process and showing leadership on policy matters that impact the health of the public. Public Health professionals are familiar with some of the select unique features of public health, 1. It has a basis in social justice philosophy, 2. Inherently political in nature 3. Has a dynamic, ever-expanding agenda (Turnock, 1997, p. 15). So should we not be prepared to defend reform that has the opportunity to protect and offer insurance to previously uninsured persons and offer a significant amount of public health prevention measures at the federal level?

Policy Process
Reflecting on the theme of the 2015 Commemorative Anniversary of the 1997 Presidential Apology for the United States Public Health Service Syphilis Study at Tuskegee and the 2015 Public Health Ethics Intensive Course at the National Center for Bioethics In Research and Health Care at Tuskegee University.

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Abstract

The Affordable Care Act: Challenges and Leadership Opportunities

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Abstract

This article stemmed from a response to the Keynote Address “The Present Socioeconomic and Health Sciences Landscape” presented by Bailus Walker, Jr. PhD., MPH, FACE at the 2015 Commemorative Anniversary of the 1997 Presidential Apology for the United States Public Health Service Syphilis Study at Tuskegee and the 2015 Public Health Ethics Intensive Course at the National Center for Bioethics In Research and Health Care at Tuskegee University.

Introduction

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Policy Process

Reflecting on the theme of the 2015 Commemorative Anniversary of the 1997 Presidential Apology for the United States Public Health Service Syphilis Study at Tuskegee and the National Center For Bioethics In Research and Health Care’s Public Health Ethics Intensive Course theme “Assuring Ethics from Generation to Generation”, forces us all to think about how each of us is learning from the past and preparing our future leaders. For example, challenges witnessed currently with the ACA share some similar challenges that were faced by policy advocates with the passage of the 1965 Voting Rights Act and its Enactment 50 years ago. Recaptured in the movie, Selma, we have the opportunity for younger generations to learn about the importance of the 1965 Voting Rights Act and the perseverance shown by prior generations in the United States to fight for social justice to ensure equity. As a reminder:

The Voting Rights Act, signed into law by President Lyndon Johnson (1908-73) on August 6, 1965, aimed to overcome legal barriers at the state and local levels that prevented African Americans from exercising their right to vote under the 15th Amendment (1870) to the Constitution of the United States. The act significantly widened opportunities for African Americans to participate in the democratic process and is considered among the most far-reaching pieces of civil rights legislation in U.S. history (History.comStaff, 2009).

Similar to our current examination of the challenges and opportunities of “The Affordable Care Act”, what can we learn from the policy process as it relates to The Voting Rights Act that can help us be advocates for the “The Affordable Care Act”? Longest indicates that the components of the policy making process are interactive and interdependent (Longest,
Articles

1. Effective outreach to populations is essential to help populations in need of enrollment into ACA the ability to understand and enroll in ACA (Adrewlust and Siddiqui, 2011). For example, the ACA includes specific provisions such as support for navigators from public and private entities to conduct public education activities- to ensure understanding by the general public around information regarding exchanges, health benefit plans and enrollment processes (Adrewlust and Siddiqui, 2011). These educational promotions of ACA are to be provided in a culturally and linguistically appropriate manner. It is important that we seek opportunities as leaders to be trained to be advocates that can run training programs in our communities similar to voter registration drives that have continued to encourage participation in the democratic process in the United States.

2. Engaging in social marketing of the ACA is critical for public health advocates. Social marketing “is the use of marketing to design and implement programs to promote socially beneficial behavior change” (Greir and Bryant, 2005, p. 319). Agency like the Centers for Disease Control and Prevention (CDC), the U.S. Department of Agriculture (USDA), the U.S. Department of Health and Human Services and many nonprofit organizations have used social marketing to increase utilization of health services and promote prevention and fight chronic diseases (Greir and Bryant, 2005, p. 319). Greir and Bryant point out despite the use of social marketing by some public health organizations, that it is still a large knowledge gap in the field of social marketing. As public health leaders we could use some of the techniques found in the social marketing filed to promote and advocate for persons eligible to enroll in ACA. Public Health Advocates can also use social marketing to highlight the successful gains made, since the start of the enactment of ACA law to help promote against some of the strong public opposition to the ACA law in the United States.

3. Leadership opportunities through Health Care Workforce Support provided by ACA. “The Affordable Care Act reauthorizes and expands a number of workforce programs that promote greater diversity and cultural competence of health care providers” (Adrewlust and Siddiqui, 2011, p. 1832). As pointed out by Dr. Cynthia Macri in her respondent presentation on “Reactions to Ethical Violations: Charity or Justice” made on March 25, 2015 at the 2015 Commemorative Anniversary of the 1997 Presidential Apology for the United States Public Health Service Syphilis Study at Tuskegee and the National Center For Bioethics In Research and Health Care’s Public Health Ethics Intensive Course, that racial or ethnic minority practitioners are more likely to respond to the high ethical violations by the health care providers. As public health leaders we have to advocate and educate the public of these opportunities and engage in helping to develop the Health Care Workforce.

Leadership Opportunities

There are many definitions of leadership. Northhouse offers a definition of leadership when looking at leadership as a process, “leadership is a process whereby an individual influences a group of individuals to achieve a common goal” (Northhouse, 2015, p. 6). The researcher’s addition to that definition is that the leader has to make sure that the common goal is ethical and moral. There is a difference. There have been plenty of examples of leaders that were able to get persons to work on a common goal however, the common goals might not have promoted social justice outcomes. As public health leaders we are expected to ensure social justice in protecting the public’s health despite as Dr. Walker pointed out in his keynote address, the ever expanding public health agenda. Many programs and schools of public health are calling on students who participate in graduation or special ceremonies at the school to recite a Public Health Professional Oath. Developed by the American Public Health Association and changed in some programs and schools to fit their missions (Krisberg, 2003). One of the keys in many of the Public Health Professional Oaths recited, is the call for placing the protection of the public’s health even before your own interest and that of your employer’s. If we believe what many other scholars in public health have indicated (Warren, Walker and others) ACA is a tremendous opportunity to promote the public’s health for those that have been uninsured and void of adequate healthcare access, than your leadership is required in the ongoing policy process. There are many opportunities to lead as public health advocates in the promotion of ACA.
Conclusion

In conclusion the researcher recalls a conversation with Dr. Bailus Walker over lunch when attending the same conference in 2013. He said, "Dr. Williams I have read ACA from cover to cover and it is a lot of public health in here man!" By the way, he was the first person the researcher knew that read the whole ACA law from cover to cover. Preventive services are in the ACA that again need our public health leadership through advocacy and promotion of this law. This will need to be achieved despite our every expanding public health agenda. At the 2015 conference we were challenged to "Assure Ethics from Generation to Generation." As the late great, Rev. Dr. Benjamin Elijah Mays, president of Morehouse College stated "Every man and woman is born into the world to do something unique and something distinctive and if he or she does not do it, it will never be done". The researcher closes by requesting you to do what you were born to do - lead.

References


Mass Incarceration of African Americans and the Social Determinants of Health Commentary: Presented March 26, 2015 National Center for Bioethics in Research and Health Care at Tuskegee University

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Author Note

The author is solely responsible for the content and opinions expressed in this article.

Abstract

This article is based on comments from an interactive panel discussion presented at the 2015 Public Health Ethics Intensive Course at National Center for Bioethics in Research and Health Care at Tuskegee University. It details the impact of the disproportionate mass incarceration of African Americans on each of the social determinants of health as identified by the World Health Organization. The article concludes with recommendations to reduce the epidemic of mass incarceration and improve the health outcomes of the impacted persons and their communities.

Introduction

The disproportionate mass incarceration of African Americans in the United States has created a devastating effect on our community. Incarceration rates in the United States have grown by 700% since the early 70’s (Kyckelhahn, 2012). There is no coincidence that the national War on Drugs began during that same time period and led to a surge of prison and jail populations that reflected disproportionate arrests in communities of color. According to the FBI Uniform Crime Report of 2014, 69% of arrestees were White and 29% Black. These percentages reflect an overrepresentation based on our population prevalence. We are more likely to be arrested and more likely to serve long sentences for drug offenses (Western and Pettit, 2010). With this failed strategy of arrests, the war on drugs was lost. There was no reduction in the prevalence of drugs on the streets and little was done to offer drug treatment or reduce the human demand for drugs. Only more prisons were built (Human Rights Watch, 2016). These prisons built in rural areas to house people of color from urban areas. This shift in census population created a political strategy to move power and reduce representation from these urban areas and to provide free labor to these rural areas. The massive influx of drugs and guns at the end of the Vietnam War further fueled the deterioration of the African American community with more violence (Chipman, K., 2001).

Another major contributor to mass incarceration was the deinstitutionalization of mental health patients that occurred during the same time as the War on Drugs. Since resources
were not redirected to the community as promised, when these institutions were closed, released individuals became homeless and the subject of frequent arrests and incarceration (Harcourt, 2011). Later, mandatory minimum sentencing laws further exacerbated the problem of disproportionate incarceration (United States Sentencing Commission, 2016).

According to David Cloud of the Vera Institute, African Americans are jailed at almost four times the rate of White Americans despite their making up only 13 percent of the U.S. population. Three out of five people in jail are not convicted of any crime and are simply too poor to post even a low bail to get out while their cases are being processed. Nearly 75 percent of both pretrial detainees and sentenced offenders are in jail for nonviolent traffic, property, drug, or public order offenses (Vera Institute of Justice, 2014). A history of substance abuse, mental illness, poverty, failure in school, homelessness and institutional racism increases the likelihood of incarceration (Vera Institute of Justice, 2014).

Impact on the Social Determinants of Health

There is a bioethical impact of mass incarceration on the health of the African American individual and upon the African American community. The social determinants of health as defined by the World Health Organization (WHO) are the circumstances, in which people are born, grow up, live, work, and age, as well as systems designed to deal with ill health” (WHO, 2016). The social determinants of health include family structure, education, economic opportunity, housing, neighborhood, or built environment, access to health care and social goods and the wider set of forces and systems shaping the conditions of daily life (WHO, 2016). All of these are major contributors to health disparities when not fully achieved. Mass incarceration is one of the major contributors to poor health within communities (Freudenberg, N., 2001). To such an extent that incarceration and criminal justice are considered social determinants of health.

A healthy life begins with a healthy pregnancy. There are increasing numbers of women being incarcerated. An estimated 6 percent of these women are pregnant, with the majority having conceived within 3 months of being released from a prior incarceration. Many of these women may not have received prenatal care while in the community and depending on the correctional facility, may not receive adequate prenatal care while incarcerated. During labor and child birth, she may be shackled (American College of Obstetrics and Gynecology, 2011). Her newborn son remanded to foster care. The baby’s father cannot be present for the birth because he is incarcerated as well. What a start in life!

As indicated earlier, family structure is one of several social determinants of health. Strong family ties and positive social connections are essential for good health (Freudenberg, N., 2001). Mass incarceration has deeply changed the structure of our families. Most people who go to jail or prison have children. There are 2.7 million children under the age of 18 living in the U.S. with at least one parent in prison (US Census Bureau, 2013). Having one or both parents incarcerated increases the chances of homelessness and poverty for that child. Increased concentrations of incarcerated African American men may result in decreased marriage rates for African American women and more single mother families. Single mother families are more likely to live in poverty. Three times as many Black children are living in poverty than white children (US Census Bureau, 2013).

Incarceration leads to loss of economic opportunity, another social determinant of health (Human Rights Watch, 2016). Even with the desire to provide for his or her family, an incarcerated prisoner within the Federal Bureau of Prison earns between 12 and 40 cents/hour cent/hour, barely anything toward family financial support and to fulfill needs inside the prison such as medical copays (www.bop.gov, 2016). If a person spends only a few days in jail, it may result in job loss and the employment application disclosure of a criminal offense resulting in lost future employment opportunities. For youth, an arrest or period of incarceration can interrupt schooling and greatly hinder completing high school or getting into college and impact negatively future employment.

Without jobs; housing, another social determinant of health, becomes marginal for the child and family. Public policies ban people with drug felony convictions from getting welfare, food stamps and even obtaining subsidized housing (Mauer, 2013). Legal debts incurred during incarceration often cannot be paid leading to poor credit ratings and difficulty obtaining home loans even years after the incarceration. With job loss and homelessness, the child and family suffer and the community is left in poverty.

Neighborhood or built environment and education are two other social determinants of health impacted by mass incarceration. Neighborhoods decay and environments are no longer safe. Schools fail and educational opportunities are lost. We must break what the Children’s Defense Fund terms the Cradle to Prison Pipeline by making early interventions in the lives of our children. Let’s reduce the violence and victimization they experience in their communities. According to the final report of the United States Attorney General Eric Holder’s Task Force on Children Exposed to Violence (www.justice.gov, 2016), “the toxic combination of exposure to family violence, child physical and sexual abuse, and exposure to community violence increases the risk and severity of posttraumatic injuries, health and mental health disorders for exposed children by at least twofold and up to tenfold.”

Data collected by the Bureau of Justice Statistics at the U.S. Department of Justice show that young black men were the most likely to be robbed and victimized by violence, including homicide which is the leading cause of death for young black males ages 10 to 24 (CDC, 2010). Although these young men are often victims of crime themselves, they do not identify themselves as such. Exposure to violent crimes leads to many physical and mental health morbidities including post-traumatic stress disorder or PTSD (Roberts, et.al. 2001). Young people exposed to violence may never fully recover and instead perpetrate violence and aggression on others (Freudenberg, N., 2001). By living with that trauma, they may need to feel safe through affiliation with gangs or other peers they feel can protect them. Exposure to the criminal justice system will only further aggravate that fear and hyper vigilance. The same young son born to the incarcerated mother and father is now trapped in a continuing cycle of poverty, arrest, abuse and ultimately an early death.
Impact on Health Care

The millions of people who cycle through the nation’s courts, jails, and prisons experience chronic health conditions, infectious diseases, substance use, and mental illness at much higher rates than the general population. Overcrowded conditions inside jails and prisons lead to violence, sexual victimization, and greater risk for the spread of infection. The 2011 Supreme Court case *Plata v. Brown* (www.supremecourt.gov, 2016) confirmed that overcrowding in California’s prison system created unconstitutional conditions and exposed inmates to increased violence and suicide, unsanitary living conditions, spread of communicable diseases, psychiatric deterioration, and medical neglect resulting in injury, illness, and death. This was not the first time the Supreme Court had made a decision specific to the health conditions in a correctional setting.

In 1976 the Supreme Court ruled in *Estelle v. Gamble* (https://supreme.justica.com), a case out of Texas, that failure to provide health care to an incarcerated person is a constitutional violation of the 8th amendment which prohibits cruel and unusual punishment. People held in correctional facilities are the only group in the U.S. with a constitutional right to healthcare based on this Supreme Court ruling. In many cases correctional facilities were the primary source of health care for uninsured young African American men (Freudenberg, N., 2001). Correctional institutions provide more care for the mentally ill than what is often available in most communities of color. Lack of insurance is the most significant contributing factor to limited access to adequate health care (Healthy People, 2010). Among adults, people of color are nearly twice as likely to be uninsured than whites.

The Affordable Care Act (ACA) (www.HHS.gov, 2016) has the potential to improve access to health care for many medically underserved populations. The ACA requires states to develop strategies for enrolling vulnerable populations into health insurance plans and coordinated care. These vulnerable populations are defined as “children, unaccompanied homeless youth, children and youth with special health care needs, pregnant women, racial and ethnic minorities, rural populations, victims of abuse or trauma, individuals with mental health or substance-related disorders, and individuals with HIV/AIDS”—, a list very inclusive of correctional populations (ACA) (www.HHHS.gov). More notably, the ACA includes coverage for substance abuse and mental health treatment services. Addressing these conditions should reduce the flow of mass incarceration from the community. The federal government prohibits use of Medicaid dollars to pay for healthcare services delivered to people in correctional facilities and the ACA does not change this longstanding rule (also known as “the inmate exclusion”).

Despite this exclusion, correctional facilities should strive to connect inmates released with chronic medical conditions to community providers as part of their reentry planning. Reactivation of Medicaid or insurance should be completed in time to ensure continuity of care and treatment upon release. Continued behavioral health services for serious psychiatric illness are essential in order to reduce recidivism. Follow up of infectious diseases such as tuberculosis and HIV will control and reduce the spread of these diseases in the African American community already disproportionately affected. Everyone should have a medical home to provide compassionate and quality care in order to improve the health of the individual and ultimately the health of the community.

Conclusion: Our Potential Impact

What can we do to ebb the flow of mass incarceration and overrepresentation of minorities? Just as Booker T. Washington lifted the veil, we must expose the social conditions that promote this biased system of incarceration. We must support family structure and community stability. We must treat substance abuse and mental health conditions which are risk factors for incarceration. We must hold elected officials accountable for harsh sentencing laws, statutes and administrative policies. We must demand non prejudicial rendering of the law. We must support policies to limit the lifespan of criminal records that assist people returning to society from incarceration to seek employment, secure housing, and enroll in social entitlement programs that are shown to protect against recidivism and improve reintegration into the community. We must insist on alternatives to incarceration such as drug courts and community supervision. We must take the lead in reducing violence and victimization in our own communities. We must support the education of our children with quality schools. We must promote expansion and implementation of the ACA. Finally, we must insist on humane conditions of confinement for those who remain incarcerated, particularly African Americans and Latino/Hispanics. Several national organizations such as the American Correctional Association (ACA.org) and the National Commission on Correctional Health Care (NCCHC.org) have correctional institution standards; yet, most jails and prisons do not comply with them or seek accreditation according to these organizations. It is up to us to work from the outside and from the inside to change a system that disproportionately incarcerates millions of African Americans, with a deleterious impact on the social determinants of health for persons, families and communities of color.


The Hip Hop Family Album: Engendering Afro-Brazilian Female Rappers

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Author Note
This article was developed from the author’s 2014 speech given in Portuguese to students and faculty at the Federal University of Ceará in Brazil. Moreover, a Portuguese version of the article is available in Artefatos da Cultura Negra no Ceará, Vol III, Editora CRV, Curitiba, Brazil, 2015. However, this English version has expanded ideas presented in both Portuguese versions. All the original Brazilian rap lyrics are in Portuguese followed by the author’s translation. The opinions represented in the article are those of the author and do not represent the views of Tuskegee University or other institution or organizations the author serves. The language of hip hop may be offensive to some readers.

Abstract
This article will examine the connection that Negra Li, Nega Gizza and Karol Conká have with the larger issues of Brazilian identity in relation to U.S. hip hop. Afro-Brazilian female rappers take center stage as MCs in a global hip hop culture where their bodies are increasingly visible, but their voices are barely audible. Negra Li, Nega Gizza, and Karol Conká show how black Brazilian women claim hip hop as a space of empowered citizenship. These hip hop artists wreck the male dominated industry with their unique styles, voices and contributions to society.

Keywords: U.S. hip hop, Brazilian Rap, Feminism, Rap

Just start to chase your dreams
Up out your seats, make your body sway
Socialize, get down, let your soul lead the way
Shake it now, go ladies, it’s a livin’ dream
Love Life Live
Come play the game, our world is free
Do what you want but scream

Planet Rock (1982)—Africa Bambaataa and Soul Sonic Force
Music and Culture

Introduction

Afrika Bambataa, DJ Kool Herc, and Grand Master Flash are arguably the founding fathers of hip hop. According to Nelson George, they are “the progenitors of the world’s dominate youth culture” (That’s The Joint!, 1998, p. 45). DJ Kool Herc, born in Jamaica, contributed the most to basic DJing technology; Africa Bambaataa, with roots in Jamaica and Barbados, contributed to the concept of a hip hop nation and the inclusion of a wide-range of musical traditions; and Grand Master Flash, born in Barbados, became a ground breaking recording artist and model of showmanship and style for many future artists (Hip Hop America, Nelson, 1998, p. 19). Political rappers like Afrika Bambaataa established organizations to protect and educate Black and Latino youth in the 70s and the 80s. Bambaataa’s idea was to educate young people about Africa, to keep them out of street gangs by participating in dancing and rap contests. In 1974, he established the Zulu Nation, an organization that still functions today (Hip Hop America, 1998, p.18). Africa Bambaata used rap to organize black nationalism and street consciousness. From the beginning, Bambaataa’s principles embraced One Love, similar to Marcus Garvey’s One God, as well as messages from Islam, Christianity, and other world religions. He was also influenced by Malcolm X and the Black Panthers, major images of Black Power during his childhood in New York. His Zulu Nation was responsible for socially conscious breaking crews, rappers, graffiti artists and a Zulu inspired fashion movement. Bambaataa established this all before the Sugar Hill Gang’s “Rapper’s Delight” in 1979. His socially conscious Zulu Nation made young people feel a part of a family and they were considered royalty. Given this range of historical influences, U.S. rap music has its roots in community building oral traditions present in Africa, the Caribbean, and of course, the African American community. Bambaataa’s early DJing included African rhythms,包括 samba, bossa nova, and other African expressions. In both sacred and profane language, rap music voices the human experience. With its diverse influences, rap music leaves the voices of women barely audible. George argues that if U.S. female artists like Queen Latifah, Missy Elliot, and Eve had never made a record, hip hop’s development would have been no different (Hip Hop America, 1998, p.184). Afro-Brazilian and African American women rap artists challenge the notion of a male-dominated industry with their unique styles, voices and contributions to society. Images of Negra Gizza, Negra Li and Karol Conká speak to a larger picture, “the hip hop family album,” in which female rappers in Brazil, in the words of the U.S. rapper Queen Latifah, wreck the male-dominated hip hop family.

Hip Hop ‘Til You Don’t Stop: Who Belongs in the Rap Game?

In their simplest terms and for political purposes, hip hop is a culture and rap is the music produced within hip hop culture. Hip hop is the umbrella term that includes the clothing, the dance, the graffiti, the DJ, the MC, the rap music and the slang that is unique to hip hop culture. Hip hop can be used as the name of a place, and thus many use the capitalized term Hip Hop Nation. Or it may be used as an adjective like hip hop music, hip hop dance or hip hop art. The larger picture is what is being said by the artist. The MC, the master of ceremony, or the emcee controls the message to the crowd and raps the lyrics. The DJ, disc jockey, controls the musical selection, volume, mixing, scratching and quality of sound. Terms, like MC and DJ, have been linguistically separated and culturally linked to male figures. That is to say emcees and DJs must be males. Groundbreaking U.S. artists of the 1980s such as MC Lyte and DJ Spinderella are examples of female artists who have dominated in these technical fields claiming center stage during rap performances. MC Lyte’s “Don’t Cry Big Girls” (1988) spins:

This is Lyte, and I’m just here to say
That I choose to express my feelings this way
Always alone, either with a microphone
Or just plainly emphasize the tone
Of my voice, cause yo, I know I’m your choice
So when I am speaking, show your gratitude
While I am teaching, I have no attitude

Here, the microphone becomes Lyte’s instrument for instruction and the stage her place of power. For DJ Spinderella, member of the first commercially successful female rap group Salt-n-Pepa, the turn table transforms the lyrics of Salt-n-Pepa. In “Let’s Talk About Sex” (1990), Salt-n-Pepa address the topic of safe sex. The group raps:

Let’s talk about sex for now
To the people at home or in the crowd
It keeps coming up anyhow
Don’t decoy, avoid, or make void the topic
 ‘Cause that ain’t gonna stop it
Now we talk about sex on the radio and video shows
Many will know anything goes
Let’s tell it how it is, and how it could be
How it was, and of course, how it should be
Those who think it’s dirty have a choice
Pick up the needle, press pause, or turn the radio off
Will that stop us, Pep? I doubt it
All right then, come on, Spin

Both the female MC and DJ speak up, but if Nelson George is correct these instances are rare in the industry and women’s voices are barely heard. If women are not heard on the stage, they can be seen dancing. Hip hop includes break dancing, b-boys and fly-girls. The b-boys break dance and the fly girls are the background dancers; they can perform but do not speak. Thus, the message is transmitted through the manipulation of male and female bodies, which can signify sex, strength, pride or vulgarity. Hip hop also includes the music video and the film industry. In the hip hop family, the industry has been dominated by men who held the microphones while women danced or sang in the background. When audiences think of Brazilian women, they have, due to North American depictions, thought of mixed-raced, exotic-representations of highly sexualized women. These women appear in the videos of U.S. male rappers, such as Snoop Dogg and Pharrell’s Beautiful (2003), where rappers describe women’s hair as “long and black and Cuban” and use language such as “big booby” to characterize their bodies. The male rappers in this video equate Cuban and Brazilian women, whom interestingly enough share a legacy of African ancestry. In “What Hip Hop Says To You Black Women?” (2015), Chakayra Conyers notes:

Tutorials provided by many of today’s “video vixens” tell me that if I make a little bit of money and add the hair follicles of a Brazilian woman’s to my own head, that stops at my a*s, I can at least be a “bad b*tch”. I can’t sit here and confirm that this is how I should actually feel, but how many of our “favorite emcees” choose to procreate with different women, of different states, never offering them any commitment? (third paragraph).
Conyers suggests that women’s place in the background is actually a dangerous space for women who subscribe to male emcees. It is a place of low self-esteem and false economic empowerment. From hip hop’s inception, the place of the Black woman has always been tenuous as the Black woman is a necessary part of the party, but not always a star player. Hip hop may be considered misogynist because women are often objectified in the music, the videos and the parties.

**U.N.I.T.Y.: The Queen of Hip Hop**

One of the first *queens* of the industry is iconic U.S. rapper Queen Latifah. Her song *U.N.I.T.Y.*, which won the 1995 Best Rap Solo Performance Grammy, urges young men to treat women with respect:

> What’s going on in your mind is what I ask ya
> But like Yo-Yo, you don’t hear me though
> You wear a rag around your head and you call yourself a “Gangsta Bitch” now that you saw Apache’s video

Queen Latifah’s song serves as a mantra against domestic violence and warns men against calling women *bitches* and *hoes*. Queen Latifah, born Dana Elaine Owens, refuses to be disrespected. She produces videos that portray her as a hardcore rapper, an MC, and a queen. In *Blue Legacies and Black Feminism: Gertrude “Ma” Rainey, Bessie Smith and Billie Holiday*, author and activist Angela Davis takes exceptions with the image of the *queen* in hip hop culture. She observes: “In hip hop culture, black women are often portrayed as ‘African queens,’ to be accorded respect by their men. What is frequently implied by the evocation of *queens*, however, is that the ultimate authority rests with the *kings*” (Davis, 1998, p. 122). While I agree with Davis that the acceptance of the term *queen* submits to the idea of a *king*, the problematic term also implies that the woman is in control of her identity. The female rapper is on the hip hop stage and she performs the identity of her choice: *queen*. As the actor of her own script, Queen Latifah remains a role model, movie star, television show hostess, producer; most of all, she remains true to herself. An engendered hip hop allows for the freedom of expression of identity for both males and females. The problem is a linguistic problem in that first, she disrupts the notion that women must sell their bodies to survive in Brazil. Her stance breaks whatever price. Nega Gizza is an emcee who encourages women to take their place on the stage; she uses her position on the stage to rap about prostitution. In a 2003 interview with Silvia Carone:

> Gizza: Acho que as pessoas têm curiosidade, porque quase ninguém fala desse assunto. Quando falam, falam de uma forma meio fantasista, tentam colocar um pouco de glamour em tudo isso, para poder ficar bonito. E acho que essa letra tem o compromisso de mostrar o que é a prostituição na realidade.

Gizza: I think that people are curious because no one has spoken about this subject. When they speak they speak in a form of fantasy and try to put it in a form of glamour so that it will be beautiful. I think the lyrics have to show the reality of prostitution. (author’s translation)

Gizza’s use of the term *beautiful* recalls Snoop Dogg’s video for the song “Beautiful” (2003) in which Brazilian women are objectified. In reality, Nega Gizza has short black hair and brown skin; she speaks for the range of Afro-Brazilian women who remain underrepresented in U.S. videos. In the hip hop industry, there is literal prostitution and figurative prostitution; literal prostitution defines how female artists, particularly U.S. female rappers, sell themselves to then sell their albums. The figurative prostitution involves how the content, the lyrics and the videos of female and male artists promote a vision of womanhood that suggests that the Black woman’s body is for sale. Black female rappers walk a fine line in determining whether they want to be MCs with a message or *pimp* selling their albums or essentially selling their bodies at whatever price. Nega Gizza is an emcee who encourages women to take their place on the stage; she disrupts the notion that women must sell their bodies to survive in Brazil. Her stance breaks with the Brazilian narrative of soccer and carnival as women emerge as empowered citizens. She maintains a not-for-profit organization in the roughest favela in Rio de Janeiro, Brazil and continues to fight for women’s rights.

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**Say my Name! Say my Name!: Who is Nega Gizza?**

Like the 80s American rapper Queen Latifah, the twenty-first century Afro-Brazilian rapper Nega Gizza looks for specific national problems and calls for an end to violence against women. Nega Gizza’s music enforces the daily reality of Brazilian life versus the imagined happiness of the Brazilian carnival— which ignores the consumption of Black female bodies. Her album title “Humildade,” which translates humility suggests the idea that she is a kind observer so her beats are melodic and her words are soft. The 1999 song “Depressão” [Depression] is hard, nervous, but never loses hope for a better future. In one verse, Nega Gizza raps:

> I’m not going back I’m moving straight down the line (author’s translation)

A que horas necessito sair vou me arrumar
Não posso mais me esconder vou continuar
Uma interrogação sobrevoa minha mente
Não vou voltar você seguir em frente
What time do I need to get ready to go out?
I can no longer hide myself I have to move about
There is a question that consumes my mind
I’m not going back I’m moving straight down the line (author’s translation)

These lyrics reflect Nega Gizza as an artist, poet and a fighter. In “Depression,” the sound heard is a classic rap sound which was present during the 1980s and 90s in the U.S. Gizza’s style is definitely hip hop with Afro-centric clothing and hair. Gizza’s song “Depression” uses more Jazz-styling and scratch technique to make the mood somber, but the tone is hard and firm. The rap song “Depression” is not sad, but determined. Unlike a lot of rap, this song is not a party song, but a song of reflection. Nega Gizza is Brazilian rapper’s MV Bill’s protégé or one could say “adopted sister.” MV Bill is known for his work against social injustice in Brazil. He is a Brazilian iconic rapper whose initials MV translate for *Messenger of Truth*. The two rappers have collaborated together to open up spaces for black women on the hip hop stage in Brazil. For the black Brazilian woman, hip hop is the freedom to be herself and fight a country who tries to sell her body and gives her nothing in return. Nega Gizza uses her position on the stage to rap about prostitution. In a 2003 interview with Silvia Carone:

> Gizza: Acho que as pessoas têm curiosidade, porque quase ninguém fala desse assunto. Quando falam, falam de uma forma meio fantasista, tentam colocar um pouco de glamour em tudo isso, para poder ficar bonito. E acho que essa letra tem o compromisso de mostrar o que é a prostituição na realidade.

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Bad B*tches: Hip Hop Feminism and Nicki Minaj

Converging with the Brazilian notion of carnival, U.S. rapper Nicki Minaj’s song “Pound the Alarm” claims ownership over other women as she invites everyone to the dance floor referring to other women as bitches. In the song and music video “Pound the Alarm” (August 21, 2012), rap artist and performer Nicki Minaj merges hip hop culture and carnival culture, and thus disrupts the notion of women’s empowerment through hip hop or hip hop feminism. I use the term hip hop feminism to suggest an empowerment available to women through hip hop only when the stage is seen as a space of economic and social elevation. Minaj problematizes my term in that her rise to power steps on the backs of other women by calling them bitches and hoes. In other words, Minaj epitomizes the problem of the African Queen/King who reigns on subjects that lack the knowledge to unlock their own social freedom. Nicki Minaj shouts:

Yo, what I gotta do to show these girls that I own them
Some call me nicki, and some call me roman
Skeeza, pleeza, I’m in Ibiza (whoa)
Giuseppe Zannotti my own sneaker
Sexy, sexy that’s all I do
If you need a bad bitch
Let me call a few
Pumps on and then little mini skirts is out
I see some good girls, I’m a turn ’em out
Ok bottle, sip, bottle, guzzle
I’m a bad bitch, no muzzle, what?
Bottle, sip, bottle, guzzle
I’m a bad bitch, no muzzle, let’s go.

Minaj is simultaneously a bad b*tch and a carnival Queen. Born in Trinidad and raised in Jamaica Queens, NY, Nicki Minaj is known for her lyrics and videos that disenfranchise women while at the same time celebrating wealth and personal freedom. With songs like “Stupid Hoc” and “Looking Ass Niggah,” she is one of the wealthiest rappers in the U.S. behind JayZ, P.Diddy and Dr. Dre. She has many alter-egos including Marilyn Monroe, Cinderella, Roman Zoolanski and herself as Carnival Queen in her family’s hometown in Trinidad. Conversely, songs like “Marilyn Monroe,” “Autobiography,” and “Sweetest Girl” seek to humanize her in an industry where consumers purchase fantasy and myth and not real lived experience in iTunes stores. Like Nega Gizza, she understands that she is in a culture that she must constantly question and a culture that many consume and eventually kill her—thus the story of Marilyn Monroe. Not surprising then, the explicit “Pound the Alarm” has political implications that escape the average video viewer. Annita Lucchessi in Racialiscious argues that Nicki Minaj’s “Pound the Alarm” Reveals Trinidadian Party Politics. According to Lucchessi (2013), “Minaj is routinely overlooked as a ‘conscious artist’ despite the fact that many of her songs, as well as her carefully curated appearance, are politically charged.”

To audiences, Nicki lives the imagined reality as a hip hop artist and Trinidadian rapper. Mikhail Baktin’s “Carnival and Carnivalesque” (1984) central ritualistic act of carnival makes the slave queen during carnival, but after the show she returns to being a slave. In essence, Minaj is not a queen of hip hop culture, but a slave to it. In the Baktian sense, the Carnival world is always encoded with cultural attack and cultural politics. The song “Pound the Alarm” like many of Minaj’s works shows grotesque realism, a gay relativity, parodied lived situation, that lacks unity in a Hip Hop movement designed to uplift people who sought to transform their lives as a collective. The mission of Africa Bambaataa Hip Hop Nation was a black conscious and racial uplift. Thus, the Caribbean based. The “Pound the Alarm” video is staged in the reality of a Trinidad that is undergoing a state of emergency. Minaj’s is reacting to a curfew set during carnival, murder rates and police brutality. The alarm is a nation in distress. If audiences gaze beyond the obvious, there are multiple levels of discourse present in “Pound the Alarm.” One, people need a party to escape distress and make political statements. Two, the celebration is not only a Caribbean tradition, but trans-historical phenomenon seen in different time periods, but trans-culturally. From a hip hop feminist perspective, the video and song instantly illustrate the perils of being queen when the position promotes performance of “male authority” supplanting a patriarchal system that puts one woman in the place to dominate other women, and thus perpetuates a culture of commercialization that immediately places women on the auction block. It is arguable if the authority of the microphone or the right to MC changes the blurred line of oppressive performance. However, if listeners consider Minaj’s story and alignment with Marilyn Monroe, Billie Holiday and Madonna, her microphone may be considered a liberating pen. There is no mistake. Nicki is no Queen Latifah, even as the queen image can be linguistically and performatively challenging—Nicki represents the flawed queen. However, in her performance of carnival, Minaj aptly demonstrates Mikhail Baktin, the double life during Carnival, which seems so appropriate for the nature of hip hop—where the American dream is always at stake and for sale. Minaj is like the end of Carnival, full of the possibility of renewal and rebirth. In “Marilyn Monroe” (2012), Nicki spins: “Truth is we mess up. Till we get it right. I don’t want to end up. Losing my soul.” Truly, Minaj resonates with Brazilian rappers in her sense of reflection and incorporation of the reality of the female body. She may represent the opposite of the Nega Giza’s activism, but Minaj sense of self-celebration strikes a cord with global rap consumers.

Let’s Get This Party Started: Karol Conká

Brazilian rapper, known to many in world music, Karol Conká, celebrates herself. She is an example of a hip hop style that merges Samba and traditional rap beats to be uniquely Karol Conká. Like Minaj, her song “Boa Noite” (Good Night) reminds audiences to know her name: she is Karol spelled with a “K.” In Portuguese, the con means with and ká is k: Conká. In the tradition of hip hop, defining one’s self is essential to knowing who you are and claiming the microphone. In the age of twentieth-first century globalization and technology, Karol Conká accesses audiences through Facebook, YouTube and Twitter to name a few. She is from Curitiba, which is a southern Brazilian state that is not historically known for its Black consciousness. However, Karol Conká positions herself as a woman of the African Diaspora. Like Nicki Minaj, she has various looks and patterns. Karol Conká album “Batuk Freak” claims the African tradition of Batuk music and the U.S. slang of freak. In English vernacular, freak can refer to one’s sexuality or one’s love for an item. Karol embraces her sexuality and her love of music. Karol Conká is a fusion of linguistic and musical experiences. Her album cover and look fuse African designs, bright colors, tigers and triangular shapes. In videos and interviews, she can
be seen with a short afro, twists, or an asymmetric-bob. In the 2014 song "Boa Noite" [Good Night], Karol Conká's good night is actually a hello to the party goers. Conká proudly shouts:

Vim para chega e dá um confere.
Sou o que o povo prefere meu estilo e o que difere.
Totalmente livre e leve ao mesmo tempo que ferve.
A batida me causa febre aquecida nada interfere.
I came to give a shout out.
I am what the people want and my style is what it's all about.
I am totally free and light at the same time hot.
My beats burn and you can't touch that. (author's translation)

Conká self-respect epitomizes the freedom available in hip hop. Unlike Nicki Minaj, audiences will not see video vixens in Conká's videos, but will see working class Brazilians out on the town. Karol was told as a young child that she was destined to become a cleaning lady (Albuquerque, 2013, paragraph 9). She is young, black, poor and from Brazil. Her celebration represents beating the stereotype for many Afro-Brazilian women: becoming cooks and maids. Conká dances, raps and enjoys the stage; while her music may not be overtly politically it does have a message. The politics of her music involve the use of African beats, Samba beats and the mixture that she brings to rap music. Some may argue that with this freedom comes a social responsibility.

**Liberation: Negra Li**

As an individual artist Negra Li recognizes the value of her color and her own story. A rap pioneer from São Paulo and the Grupo R.Z.O., Negra Li never forgets her hip hop roots. However, she refuses to be limited by any masculine or industry definition. Her 2012 album *Tudo De Novo* (Everything Again) attempts to recreate her image and give her a new sound outside of rap. Negra Li, like U.S. rapper Queen Latifah, remains a symbol of the black women's presence in the Brazilian hip-hop industry. Negra Li has survived in the hip hop mainstream as well as in Brazilian TV and film industry. Negra Li literally translates as Black Woman Li or simply put Black Li. In the 2006 film *Antônia*, Negra Li portrays Preta [Black], a black woman, struggling to survive as a hip hop artist in Brazil. The character Antonia faces the violence, the sexism, and the poverty of Brazil. Moreover, Preta struggles as a mother trying to raise a daughter in Brazil. Other characters in the film face similar challenges, however, the music bonds them together. While the group Antonia sings “Killing Me Softly” in the film, Lauryn Hill's song “Every Ghetto, Every City” characterizes the struggle of the Brazilian favela (slum) and the hope of hip hop:

I was just a little girl
Skinny legs, a press and curl
My mother always thought I’d be a star
But way before my record deal,
The streets that nurtured Lauryn Hill

From her own album, Negra Li's song "Negra Livre" (2006) expresses her own black consciousness. Negra Li raps:

Está na cara, a cor,
as sombras das imagens.
Em tudo o que supor, nos contos, nas miragens.
A minha voz linda.
It's in the face, the color, the shade of
Of the images. In everything you can imagine, the stories the mirages.
My beautiful voice.

Negra Li articulates that her true beauty lies in her voice not in her body. In videos, she wears her hair in natural styles like braids and afros; she appears to embraces her African-ness. Like Hill's “Every City, Every Ghetto,” Negra Li implies that her real freedom is in her ability to tell a story. This consciousness shown from *Negra Li* in her name to *Negra Livre* in the song title speaks volumes to her growth as an artist and her value as an MC. *Negra Li* is her artist’s name, which evokes race; the song title *Negra Livre*. The translation Free Black Woman shows transformation, liberation and self-determination. Both Lauryn Hill and Negra Li have experienced commercial success and transformation.

**Conclusion: Dropping the Mic**

Rap must do more than sell records and buy homes. There is hope in hip hop, but men and women must come together. Negra Li, Negra Gizza and Karol Conká come from spaces in which their music valorizes their own beauty, their own stories, and their own Brazilian lives. Yet, Brazil is faced with senseless violence and corruption. Afro-Brazilian artists look towards the West to understand social action with heroes such as Malcolm X and Martin Luther King. Like the rest of the world, they watched, during August of 2012, video of an unarmed Michael Brown being killed by police officer Darren Wilson in Ferguson, Missouri. A grand jury voted not to indict Darren Wilson in November of 2014. This event sparked national protest about police violence against communities of color in the United States and brought national attention to the Black Lives Matter Movement around the world. Global artists began to see how the hip hop family could function as an agent of social protest. U.S. rapper J. Cole wrote the rap song “Be Free” (2014) in response to Michael Brown's death. An excerpt of the song is as follows:

All we wanna do is take the chains off
All we wanna do is break the chains off
All we wanna do is be free
All we wanna do is be free
Can you tell me why
Every time I step outside I see my niggas die
I'm lettin' you know
That there ain't no gun they can make that can kill my soul
Oh no
J. Cole’s somber song seeks freedom from society’s chain. He speaks first for himself and then for the collective. The hip hop slang nigga is his cry for his brothers who are lost to the violence. The language is problematic, but nonetheless it is the emcee J. Cole’s reality. The word nigga implies the historical violence that White America has performed against Black Americans bodies beginning with the Atlantic Slave trade. The word nigga sparks rage in many African Americans. Yet, linguistically and culturally, Brazilian rappers Nega Gizza and Negra Li would need an exchange of histories to understand the etymology of the English slang nigga in J. Cole’s song. Their names both sound like the English word. Given the history of the word, which involves lynching and the denial of civil rights to Black in America, J. Cole’s refrain “all we wanna do is take the chains off” makes perfect sense in both cultures and in both languages: livre means free in Portuguese. The word livre is essential to how Negra Li sees herself and her music in an age of global consumption. Her music no longer belongs to Brazil, but it belongs to anyone with access to YouTube. Realizing that she too is a part of the message, Lauryn Hill also dedicates her 2012 song “Black Rage” to Michael Brown. She sings:

Victims of violence
Both psyche and body
Life out of context IS living ungodly
Politics, politics
Greed falsely called wealth
Black rage is founded on denying of self
Black human packages
Tied and subsistence
Having to justify your very existence
Try if you must
But you can’t have my soul
Black rage is founded on ungodly control
So when the dog bites
And the beatings
And I’m feeling so sad
I simply remember all these kinds of things
And then I don’t feel so bad

Both Cole and Hill speak to the human experience and the soul. Lauryn Hill plays on the happy song “A Few of My Favorite Things” to characterize human behavior that leads to Black rage. Materialism, capitalism, and violence are a few things that exist both in Brazil and the United States. Inevitably, greed, overconsumption and the commodification of black bodies can lead to terror and rage in supposedly free societies. Living out of context, which is the epitome of Brazilian carnival, weakens the Black psyche; but both J. Cole and Lauryn Hill resist having their souls overcome by the inhumanity of police brutality nor do they lose self-control. Nega Gizza’s music also speaks to moving forward in spite of the pain. The stance articulated in the music of conscious hip hop artists mirrors the Black Lives Matter movement in which protestors seeks to highlight the value of the victims’ lives by staging peaceful protests. J. Cole and Lauryn Hill articulate hip hop’s response to police violence. The empowered citizen’s response was to march, to raise money for scholarships and to educate the masses against violence. J. Cole’s “Be Free” and Hill’s “Black Rage” songs invoke soul. Socio-linguistically, the term Soul music, with a capital S, encompasses the diasporic nature of African American music that spread to Brazil from the United States and around the globe. Today more than ever, Soul calls for a united protest and understanding as global mothers are losing their sons and daughters to violence. The hip hop family becomes critically important as socially conscious artists must drown out the noise made by artists who sell bodies and mute voices. Hip hop artists urge audiences to think before they act, but they must act responsibility to be free. Youth are relying on conscious parents to help them make wise decisions from the place they go to the hip hop artists to which they listen. Michael Brown is only one of many youth to die due to police violence. His mother is only one mother of many mothers to face the media and ask: “Why my son?” or “Why my daughter?” Afro-Brazilian poet Elisa Lucinda (2000) recognizes the value of her four-year-old son’s voice:

Mãe, sabe por que eu gosto de você ser negra? Porque combina com a escuridão. 
Entrão, quando é de noite, eu nem tenho medo. 
...Tudo é mãe e tudo é escuridão (Lucinda, 2000, p.118)

Mom, know why I like that you are Black? 
Because you are like the nighttime. 
So when it is night, I am not afraid. 
...Everything is Mom and Everything is dark. (author’s translation)

As a young boy, the Black poet’s son sees his mother as beautiful. Her blackness is a sense of safety, love and pride. In contrast to Snoop Dogg’s use of the term beautiful, the hip hop family must begin with Bambaataa’s notion of “One Love” as evidenced by the works of Negra Li, Nega Gizza, Lauryn Hill, and Queen Latifah. Not all female artists will fit the model of socially conscious hip hop, instead these women will seek to celebrate themselves such as Nicki Minaj and Karol Conká and hopefully encourage other women to value their voices as they stake their claim in the hip hop industry. The late U.S. poet Laureate Maya Angelou spoke to a global Black consciousness and a resistance to violence. In the poem “Still I Rise” (1978), she reminds citizens:

I am a Black ocean leaping and wide. 
Welling and swelling I bring in the tide. 
Leaving behind nights of terror and fear 
I Rise.

Afro-Brazilian and African American female rap artists claim their space on the hip hop stage by picking up the microphone to celebrate blackness and to protest against violence. Additionally, black women celebrate the freedom to choose who they want to be sexually. Angelou’s “Still I Rise” challenges that a women’s sexiness can challenge the dominant discourse and notions of power. Angelou croons: “Does my sexiness upset you?” Queen Latifah, Karol Conká, Nicki Minaj, Negra Li, Nega Gizza and Lauryn Hill are only a few Black hip hop women from Brazil and the USA who are making audiences think about who they are and who they want to be.
References


The Philosophical Relevance of the Negro Spirituals

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Abstract

This article is purported to bridge a lacuna in the scholarship on the Negro spirituals. Hitherto, scholars and commentators on the spirituals have focused almost exclusively on the religious dimensions of the songs to the total exclusion of the songs’ philosophical import and relevance. This article is sui generis in that it effectively eliminates the conspicuous absence of the philosophical relevance or import of the spirituals. The article is considered seminal by virtue of its exclusive focus on the philosophical analyses of the spiritual as well as its relevance to bioethics. The author considers Booker T. Washington’s preference for, and usage of, the term “Plantation Songs” or “Jubilee Songs” and his total rejection of the appellation “Negro Spirituals” as appropriate. This seminal article analyzes the spirituals and distills the philosophical relevance embedded in them as they relate to metaphysics with specific relevance to philosophical theology. The author also distills from the spirituals the philosophical relevance or import of the spirituals. The article is considered seminal in that it effectively eliminates the conspicuous absence or import of the spirituals.

Introduction

Booker T. Washington, in expressing his sentiments and paying tribute to the immeasurable qualitative significance of the American Negro Spirituals, was actuated ineluctably to declare thus: “For myself, though it has been my privilege to hear some of the best music both in Europe and America, I would rather hear the jubilee or plantations songs of my race than the finest chorus from the works of Handel or any other of the great composers that I have heard.” (Washington, 1972). And, W.E.B. DuBois, in studying the Negro spirituals, concluded inevitably that “The Spiritual still remains as the singular spiritual heritage of the nation and the greatest gift of the Negro people” (DuBois, 2007). These sentiments or declarations emanating, as they do, from two (2) personalities of unquestionable national and international stature and fame but who, on tactical and philosophical grounds, were ostensibly and undeniably diametrically opposed to each other, are indeed significant. The significance lies in the fact that both individuals converge in toto in their estimation or valuation of the Negro Spirituals’ place vis-à-vis American culture, history and indeed, American fine arts. Washington’s and DuBois’ sensibilities to the intellectual and sentimental assessments of the spirituals provide a maximally significant motivation for others to accept the truism and validity of their conclusion regarding the immeasurable worth of the spirituals.

Propaedeutic to the central task of analytically delineating the philosophical relevance of the Negro Spirituals, it is necessary to discuss briefly the term “Negro Spirituals.” This term as employed to refer to the songs sung by African Americans since the earliest days of slavery, is demonstrably somewhat misleading. The Concise Oxford Dictionary (Pearsall, 1999), defines “spiritual” as “of relating to religion or religious belief. Also, Negro Spirituals, a religious song of a kind associated with Black Christians of the southern US.” The lexical meaning provided here is obviously a narrow one.

As Booker T. Washington has appropriately observed and commented, “Whenever companies of Negroes were working together, in the cotton fields and tobacco factories, on the levees and steamboats, on sugar plantations, and chiefly in the fervor of religious gatherings, these melodies spring into life” (Washington, 1979). The gravamen of evidence suggests that the songs were sung “during work time, play time, and rest time as well as on Sundays at praise meetings” (Gates Jr. and McKay, 1997). Thus, in the earliest days of slavery, the dichotomy between secular and sacred was not as pronounced as the lexical meaning of the term “spiritual” would necessarily connote. Perhaps, it is because the term “spiritual” as employed in “Negro Spirituals” is somewhat misleading or it is because of the term’s opacity that prompted Booker T. Washington to effectively refrain from employing it. Rather, Washington invariably preferred to refer to the so-called Negro Spirituals as “Plantation Songs” or “Jubilee Songs.” Washington’s use of the term “Plantation Songs” instead of the commonly employed appellation “Negro Spirituals,” was his conscious attempt to avoid using an opaque and misleading term.

However, DuBois unequivocally prefers to employ the term “Sorrow songs” rather than the common terminology “Negro Spirituals.” Thus, Chapter XIV of his classic book Souls of Black Folk, a chapter devoted exclusively to an analytical exposition of the spirituals is titled “The Sorrow Songs.” However, DuBois’ title is arguably misleading. Indeed, not all the songs sung by the slaves would substantively or qualitatively qualify as legitimate candidates for the title chosen by DuBois for not all the songs were sorrowful. If they were, I am inclined to submit that Washington would not have described the songs in the manner he described them namely, “Plantation Songs” or “Jubilee Songs.” Hence, the term “Plantation Songs” as employed by Washington is not only less problematic but also more accurate as a titular ascription.

The Negro Spirituals have persistently and without exception been described as “religious songs.” For example, in The Norton Anthology of African American Literature, (Gates, Jr. and McKay, 1997), the distinguished editors write: “Negro Spirituals are the religious (emphasis mine) songs sung by the African Americans since the earliest days of slavery...” Whilst this description is, prima facie, generally correct, it is, however, significantly somewhat misleading. The so-called Negro Spirituals, pace the distinguished editors, are not just religious” songs, or in the words of DuBois, “Sorrow Songs”; they can be shown upon careful scrutiny and analysis to be fundamentally imbued with philosophical relevance – a fact that unfortunately has hitherto been effectively ignored by virtually every commentator or researcher on the slave songs.
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Since a diligent search of the literature on the slave songs sadly reveals a conspicuous absence of any previous attempts by commentators at philosophical analysis of the Negro Spirituals, it is therefore my primary objective in this essay to delineate the philosophical ideas or themes embedded in the songs. This study, therefore, is presumptively sui generis in its objective and approach. In this essay, I argue, contra mundum, that the Negro Spirituals are fundamentally imbued with significant philosophical ideas and that the non-recognition or conspicuous absence of this fact in the literature on the slave songs constitutes a serious lapse in scholarship. Arguably, this lacuna devalues, in important ways, the qualitative significance of the Slave Songs. Thus, this essay aims, inter alia, to bridge or fill a serious gap in the existing scholarship on the subject by eliminating the omission referred to, supra.

Metaphysics

Philosophical Theology:

One finds in almost all of the Negro Spirituals superabundance of explicit references to “God,” “King Jesus,” “Lord,” or to themes in the Hebrew-Christian Bible, generally. This fact constitutes an incontrovertible affirmation of the Negro slave’s unequivocal belief in the existence of a supreme being, namely, God, and in one whose ontological status is characterized by certain metaphysical and essential attributes such as “enforcer of universal justice,” “a liberator of victims of evil,” a “guardian of freedom,” and a “source of hope.”

Without doubt, the most obvious philosophical significance of the Negro Spirituals is that the songs’ unequivocal affirmation of the existence of God and the total repudiation of atheism and agnosticism. The Negro slaves expressed their firm belief in the existence of God, principally the Old Testament God and similarly, a belief in Lord Jesus largely by both explicit and indirect references to Him in such songs (spirituals) as “Were You There When They Crucified My Lord?”, “My Lord! A Writin’ All de Time”, “Nobody Knows de Trouble I See”, “Steal Away to Jesus”, “O, Freedom!”, “ Didn’t My Lord Deliver Daniel?”, among others. The Negro Spirituals’ unambiguous assertion of their firm belief in the existence of God is fundamentally both philosophically and culturally significant.

The Negro Africans who were deracinated from their native lands on the Continent of Africa and enslaved in the New World (America) among other places, clearly lacked literacy, according to Western standards and in their new home, the nefarious Jim Crow laws affirmed by infamous judicial pronouncements such as Plessy v. Ferguson (1896), and public and political sentiments denied the slaves opportunity of an education. Thus, the fundamental epistemological question arises: What is the origin of the Negro slaves’ knowledge of God’s existence as explicitly expressed by the slave singers in the spirituals?

The indigenous African knowledge of God is traditionally expressed in oral literature namely, in proverbs, songs, art, prayers, myths, stories and religious ceremonies. It is suggested that all those are easy to remember and pass on to other people, since there are no sacred writings in traditional societies (Mbti, 1969). The logical inference therefore is that one should not expect a long dissertation about God. However, it has interestingly and authoritatively been stated, in no uncertain terms, that “God is no stranger to African peoples, and in traditional life there are no atheists (Mbti, 1969). I posit, therefore, that if in African traditional life there are no atheists, then a fortiori there are no agnostics in traditional life.

The truism of this statement is authoritatively summarized in a famous Ashanti proverb: “God needs no pointing out to a child” (Danequah, 1968). This indigenous African proverb means that everybody knows of God’s existence almost by instinct, and even children know Him. The epistemological or philosophical relevance of this maxim’s truism is that the African slaves who were forcibly transported to America, and their descendants, possessed an innate knowledge of God’s existence – knowledge which is clearly expressed in almost all the spirituals. Hence, the most obvious philosophical relevance of the Negro Spirituals is that the Plantation Songs (to employ Washington’s terminology) absolutely repudiate atheism and leave no room even for the slightest embrace of agnosticism. And they explicitly affirm, in no uncertain terms, a belief in the existence of God. Thus, we find in the philosophical theology of the Negro Spirituals an ontological argument for God’s existence based on self-evident truth.

One of the arguments for the existence of God in both Western and African philosophical theology is the cosmological argument. The argument’s aim is to persuade us to accept the conclusion that God is the Creator of the World. A justification in Western philosophy for regarding God as the Creator of the World is the Principle of Universal Causation. The principle holds that whatever exists must have a cause. If every event has a cause then the world must also have a cause. And God is the prime mover or initial cause, i.e., Creator of World.

The Negro Spirituals are conspicuously absent or devoid of any explicit references to God as the Creator of the World. This omission, I am inclined to believe, indicates that the belief that God is the Creator of the World is merely assumed by the slave singers in the spirituals. Who else could have been the Creator of the World, if not God?

A close examination of the majority of the Negro Spirituals ineluctably discloses a familiar truth in philosophical theology. The Negro slaves, in no uncertain terms, ascribe to God the essential and intrinsic attributes of omnipresence, omniscience, omnipotence, and omnibenevolence. We find these attributes explicitly expressed in such spirituals as: “My Lord’s A Writin’ All de Time.” In the last stanza of this spiritual, for example, the Black slaves sing thusly:

Oh, He sees all you do, He hears all you say.
My Lord’s a writin’ all de time,
Oh, He sees all you do, He hears all you say.
My Lord’s a writin’ all de time.

The fundamental philosophical insight one gathers from the dramatic language of this song is that everyday man stands completely naked, absolutely unclothed before God’s awesome and ubiquitous presence. Every moment, God’s all-seeing eyes search us to the very depths. Indeed, we stand completely revealed – revealed not just in our actions but also in our thoughts. And, indeed, to the extent that the slave singers firmly affirm the belief that God is constantly and meticulously jotting down or recording all the actions and thoughts and statements of everyone, to that extent we are accountable to God, the Creator of the World. Herein lies another philosophical relevance of the spiritual. Through the song, we are warned to be careful about our utterances and actions, about what we say and do to our neighbor. The hidden relevant philosophical message, then, that needs to be unveiled is that those who engaged in the utterly hideous practice of slavery and its concomitant acts of man’s inhumanity to man inevitably must answer to God for their unethical and immoral misdeeds. From the philosophical perspective then, “My Lord’s A Writing All de Time” is on one level, a warning and a protest against unethical
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conduct; on another level, it is a spiritual intended for man to search his or her own conscience and urge him to pursue the path of ethical conduct for conscience is undeniably an important ethical paradigm or standard for evaluating the morality of human actions or conduct.

A similar spiritual imbued with philosophical relevance may be cited as follows:

Dere's No Hidin' Place Down Dere,
Dere's No Hidin' Place Down Dere.
Oh, I Went to the Rocks to Hide My Face,
De Rocks Cried Out, "No Hidin' Place;"
Dere's No Hidin' Place Down Dere,
Poor Sinner Man, He Stumbled and Fell,
He Tried To Go To Heab'n, But Had to Go to Hell
Dere's No Hidin' Place Down Dere.

The philosophical theme undeniably distilled from this spiritual is consonant with that embedded in "My Lord's A Writing All de Time". The spiritual portrays with clarity the omnipresence and omniscience of God and, by logical inference or extension His omnipotence. Consequently, no man can ultimately and permanently hide. Arguably then, the philosophical relevance of the spiritual in question is that man is completely naked; hence he is accountable to God for his unethical conduct and actions.

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In West Africa, for instance, Divine Omniscience is expressed in the appellation (Huntanhundi) meaning (He who sees the hidden). To the Akan of Ghana, God is known as "He who knows and sees all" (Danquah, 1968), and it is a common saying among the Yoruba that "only God is wise" and they believe that God is "the Discerner of hearts." God is "He who sees both the inside and outside of man." (Idowu, 1962). He is also described as having long ears (The Ila). The Akan consider God to be able to count the footsteps of a deer on the driest rock. As we know, the deer is a light-footed animal, and it hardly leaves the traces of its footsteps even on ordinary ground. But God can, in His omniscience and therefore his omnipotence, trace and count accurately all the footsteps of a deer on the driest rock. The philosophical beliefs and themes embedded in the Negro spirituals are therefore fundamentally identical to those of the slave singers' ancestors.

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In addition to the philosophical themes we have sketched, we have identified several equally important (if not more important) themes of philosophical relevance in the Negro spirituals. These themes are philosophically relevant because, first, they are core issues in philosophy generally; second, they are dominant in the spirituals. The slave-singers often sang about the desire for freedom, and the desire for justice.

In the spirituals, the fundamental and intrinsic moral attribute of "enforcer of justice" is ascribed to God and the philosophical concept of justice is dramatically discussed. In the spirituals, references are made to the all-important and cherished idea of freedom. For example, in "Swing Low, Sweet Chariot, Coming for to Carry me Home" – perhaps the most beautiful of all the Negro spirituals, we find the profound urge to escape from the jaws of slavery into the land of freedom couched in a ballad of poetic beauty. The appeal to the theme of freedom is also found in the spiritual entitled: "Oh, Freedom!" We quote the first stanza in its entirety:

Oh, Freedom,
Oh Freedom,
Oh, Freedom Over Me!
An' Befo' I'd be a Slave
I'll be Buried in my Grave!
An' go Home to My Lord an' be Free.

In the spirituals, the eternal and intrinsic attribute of God's transcendence is balanced with that of His immanence since the two (2) are paradoxically complementary. Hence, God is portrayed as a liberator who is involved in human history, notwithstanding His essential transcendental attribute. Furthermore, the stress placed on the axiology of freedom as a core philosophical value and theme, and the celebration of freedom are expressed in direct and stark fashion in such spirituals as:

And, consider also the spiritual:

Didn't My Lord Deliver Daniel?
Deliver Daniel, Deliver Daniel?
 Didn't My Lord Deliver Daniel?
Deliver Daniel, Deliver Daniel?

We believe no spiritual’s lyrics speak more explicitly about the hardness and harshness of the slave’s life and the “many thousand” gone to the unknown fate of the auction block, gone to death. Further, the slaves’ infinite longing for peace, freedom, and tranquility is plaintively uttered in the following spiritual:

I know moon-rise, I know star-rise,
Lay dis body down.
I walk in de moonlight, I walk in de starlight,
To lay dis body down.
I’ll walk in de graveyard, I’ll walk through de graveyard,
To lay dis body down.
I’ll lie in de grave and stretch out my arms;
Lay dis body down.
Thus, the slave singer yearns for freedom and peace and cries out as a victim for deliverance from the evil of oppression, man's inhumanity to man and servitude. Arguably, then, the submission can be made that the slave-singers were the first Black Civil Rights activists and protesters in America who engaged in their civil rights activism through the quiet medium of the deeply philosophical songs called the Plantation Songs (Booker T. Washington's appellation) or Negro spirituals (the common reference).

Justice

In exploring the philosophical relevance of the spirituals, references to the theme of Justice are conspicuous of their presence. Dominant in the spirituals is a profound faith in and urgent appeal to, the ultimate justice of things. Thus, in the song, “You goin’ to Reap Just What You Sow”, the slave-singers invoke the Immutable Law of Retributive Justice. We distill from the spirituals the idea that God makes justice for both the righteous and the unrighteous, for as the spiritual says “All God’s Children Got Wings” and “Everybody who’s Talking About Heabren Ain’t Going” and anyone who stands against liberation from the yoke of slavery is called into account.

Of equal philosophical relevance vis-a-vis the central position the idea of justice occupies in the spirituals, consider this song:

“I’m Gonna Tell God All My Troubles,
When I go home ...
I’m Gonna Tell Him the Road was Rocky,
When I Get Home.

In this song, we are offered philosophical visions of justice, peace and tranquility as well as an implied critique of intolerable worldly violence and injustice.

The philosophical themes that are identified and explored in the spirituals have their origins in the traditional African culture, particularly in the culture of West Africa where most of the slaves descended. Thus, for example, the belief in the ultimate justice of things as expressed in the spirituals is identical to the native African people’s conception of God as the ultimate judge. He who metes out ultimate justice in the form of punishment and rewards.

Philosophical Visions of Hope

Notwithstanding the incontrovertible fact that the spirituals contain aspects of resentment, bitterness, revenge, and indeed protest, nevertheless one finds the philosophical element of hope also embedded in them. Consider, for example, the following spirituals:

a. Soon I Will Be Done With the Troubles of the World,
Troubles of the World, The Troubles of the World,
Soon Will Be Done With the Troubles of the World
Goin’ Home to Live With God.

b. A-settin’ Down With Jesus,
Eatin’ Hone and Drinkin’ Wine,
Marchin’ Round de Throne,
Wid Peter, James and John.

c. Steal Away, Steal Away, Steal Away to Jesus
Steal Away, Steal Away Home,
I ain’t Got Long to Stay Here.

In these songs the slaves had strong philosophical visions of hope for a better life, in a better realm.

The Unequivocal Belief in the Dignity Of Man and in the Equality of All Men

Human history is replete with superabundant examples of acts of man's inhumanity to man. And, in America; the highest court of the land was complicit in the denial of the intrinsic worth human dignity of the slaves. Notwithstanding the denial of human dignity to the slaves, contra mundum, under color of right, the slaves themselves never wavered in their affirmation of their human dignity nor did they succumb to a devaluation of their dignity. The slaves’ unequivocal belief in the dignity and intrinsic worth of man is attested to and affirmed in the following spiritual entitled “O Glory, Glory, Hallelujah!” and it runs thus:

O Glory, Glory, Hallelujah!
O Glory, Glory to That Lamb;
O Glory, Glory, Hallelujah!
Child of God, That’s What I Am!

He Leadeth Me into Green Pastures,
Child of God, That’s What I Am!

He Leadeth Me Beside Still Waters,
Child of God, That’s What I Am!

That the slaves’ unequivocal declaration that they were children of God is both culturally and philosophically relevant. The cultural relevance is demonstrably associated with the slaves progenitors’ or African ancestors’ belief that they are children of God. The Akans of Ghana, who are believed, on good historical authority, to be ancestors of a great number of the slaves forcibly transported to the New World (America) have the following well-known proverb: Nnipa nyinaa ye Onyame mma, obi nye aase ba. (All men are children of God; no one is a child of the earth). (Danquah, 1968). From this famous Akan proverb, it may be inferred the conception of humans as theomorphic beings embued in their nature with an aspect of God. The similarity between this well-known Akan proverb and the Negro spiritual quoted above with particular reference to the line “Child of God, that’s what I am!”, is evident. What emerges from this view or characterization of man is the belief, I think, that man is necessarily intrinsically valuable and precious being a child of God as he claims for it will be an oddity and logically inconsistent for God to deliberately create, contrary to His nature, a child that is intrinsically worthless. This Akan proverb and, similarly, the spiritual have both moral and philosophical overtones in that, arguably, there must be something intrinsically valuable in God for everyone to claim to be His child. Man, being a child of God, as affirmed by both the well-known Akan proverb and the spiritual quoted, indeed, would also be intrinsically valuable and consequently he is an end in himself (the Kantian Categorical Imperative) and, therefore, must not be used as a means to an end. Thus, the slave-singer’s philosophical affirmation that slavery was morally wrong; hence absolutely condemnable.
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Perhaps the best way to illustrate the philosophical relevance of the instant spiritual having regard to the declaration, "Child of God, that's what I am!" is by invoking Immanuel Kant's philosophical exposition of the Categorical Imperative. In his philosophical classic, Grundlegung zur Metaphysik der Sitten, Kant, one of the greatest philosophers in modern thought, propounded two (2) formulations of moral principles that can be applied to rational agents in determining the morality of an act i.e., whether an action is morally right or morally wrong. These two (2) formulations taken conjointly are known as the Categorical Imperative. However, it is the second version of the Categorical Imperative that has particular philosophical relevance in this essay. Kant's second formulation states:

Act so that you treat humanity, whether in your own person or in that of another always as an end and never as a means only.

On Kant's view, human beings have an intrinsic worth, i.e., "dignity," which makes them valuable "above all price." If their value is "beyond all price," it follows that rational agents must be treated "always as an end and never as a means only," This means that we have a strict moral duty of beneficence and the obligation of non-maleficence towards other persons. We must strive to promote their welfare; we must respect their rights, avoid harming them and indeed, generally endeavor, so far as we can, to further the ends of others. Ergo, slavery was morally wrong or objectionable on moral grounds.

Kant's idea has a deeper moral implication. The beings Kant is referring to are rational, autonomous beings. Thus, we may never manipulate people, or use people, to achieve our purposes. This, according to Kant, is morally wrong, because it is inconsistent with or is violative of the Categorical Imperative. This, we submit, is the fundamental philosophical reason why, as children of God the United States Public Health Service Study of Untreated Syphilis in the Negro Male in Macon County, Alabama, and the Guatemala study, for example, were unethical.

Additionally, implicit in the idea of man being a "child of God" is the notion of equality. That is to say, the idea of equality can be distilled from the Negro spiritual under consideration. A careful reflection inexorably leads to the inevitable and reasonable conclusion that through the undying belief as being children of God, in much the same way as did their African progenitors as attested through the famous Akan proverb quoted, the slaves knew instinctively that before the God who made them, all men were equal. Hence, this spiritual is imbued with the philosophical relevance of the idea of equality. Indeed, it would be logically self-contradictory to hold on the one hand that a person is a child of God and on the other hand to assert that not all children are equal before God or to hold that some children are equal and some are not before Him who created them. That all men being children of God are equal would seem to be, prima facie, both intuitively true and logically valid. In sum, the spiritual "O Glory, O Glory Hallelujah!" ... Child of God, that's what I am!" is imbued with the slaves' firm belief both in the dignity of man and in the fundamental belief in the equality of all men.

The Negro Spirituals and Negro Humanism

A microscopic examination of the Negro spirituals seems to reveal an humanistic orientation. The term "Humanism" as first coined by the early nineteenth-century German educator F. J. Niethammer means an education based on the Greek and Latin classics. However, by Humanism, I don't mean the Niethammerian sense of that word. By the philosophical term "Humanism," I mean most generally, any philosophy or view that emphasizes the importance of human dignity, welfare and values.

Some of the Negro spirituals seem to express in stark terms the philosophical idea of humanism. In the Spiritual "O Glory, Glory Hallelujah!", the slave-singers proclaim thus "Child of God, That's What I Am!" The conviction and indeed the assurance that they were children of God gave the Negro slaves an indestructible sense of dignity and a sublime or divine sense of security. The idea and belief expressed in this spiritual that although they are victims of abominable servitude and injustice nevertheless in the eyes of the God of the Universe who created them they always possessed worth and dignity. They were indeed "somebody". This Spiritual, therefore, represents a classic expression of philosophical humanism.

To say that Child of God, that's what I am, is not to deny that the slave master is a child of God. All men, irrespective of their race, color, social and economic status and education are Children of the Same God. Thus, the slave singer unequivocally affirms the equality and worth of all men in consonance with the concept of humanism.

The argument can be advanced here that the Negro spirituals taken collectively can be understood as condemning segregation and its concomitant dehumanizing effects and thus the message embedded therein and portrayed by them (the spirituals) pre-echo not only Kant but also Martin Buber.

Buber, the Jewish existentialist philosopher in contemplating the meaning of life in his classic philosophical magnum opus entitled Ich und Du can be understood as propounding the argument, inter alia, that segregation substitutes an "I-it" relationship for an "I-thou" relationship and ends up inevitably relegating persons to the status of things or objects. Hence, segregation is both morally wrong and sinful. The Buberian analysis or argument here adumbrated is similar to the Kantian formulation of the categorical imperative presented earlier.

Additionally, Paul Tillich, the German-American theologian and philosopher, has said as the late Martin Luther King, Jr. has noted in his much-quoted Letter from Birmingham Jail that sin is separation (King, Jr., 1963). Thus, it can be inferred that segregation is an existential expression not only of man's awful and tragic separation but also his unwarranted estrangement and sinfulness (King, Jr., 1963).

The Negro Spirituals and Bioethics

One of the most important utilities of the Negro spirituals is their connectedness to Bioethics. Etymologically, bioethics can be properly viewed as being about life. If bioethics is viewed in this sense, given the prefix "bio" derivable from the Greek word "bios" meaning life in general, then the philosophical relevance of the Negro spirituals to bioethics becomes non-opaque or non-obtuse.

The nature and character of the institution of slavery can only be imagined by those who have not fallen victims to it. Those who are obvious victims of it cannot, by necessity, imagine it. They experience it. And, episodic narratives and reports (both oral and written) of
the nature and character of slavery by former or freed slaves epitomize man’s inhumanity to man and senseless and abominable violations of natural, moral, and human rights of human beings.

The insalubrious environment within which the Negro slaves lived and were made to labor by their slave-masters, in particular, and the society at large in which they inhabited compelled them by necessity to contrive an ingenious modus vivendi in order to survive in this superlatively hostile and oppressive environment. Thus, the spirituals were contrived as modi operandi for human survival. From sunrise to sunset when the human soul is so oppressed and the life of man is forcibly brutalised, the Negro slaves’ insatiable natural desire not only to live but also to survive from day to day compelled them to contrive the spirituals. The Negro spirituals indeed served to soothe the soul and to act as an efficacious panacea for survival. Clearly then, the soothing of the soul and the panacean action of the spirituals served a very useful bioethical purpose. The relevance of the spirituals to bioethics or the connectedness of the former (spiritual) to the latter (bioethics) lies in the overpowering or in the conquering of the hostile environment and the ultimate survival of the slaves brought about by the repeated or daily singing of the Plantation Songs. Indeed, as Booker T. Washington has authoritatively stated “wherever companies of Negroes were working together, in the cotton fields and tobacco factories, on the levees and steamboats, on sugar plantations, and chiefly in the fervor of religious gatherings, these melodies sprang into life.” (Washington, 1979). Washington has also authoritatively written and accurately observed, in no uncertain terms, that “in the days of slavery, the Plantation Songs furnished an outlet for the anguish of smitten hearts.” (Washington, 1979). The Plantation Songs are, in Washington’s view, “an outgrowth of oppression and bondage.” (Washington, 1979).

That the spirituals were sung not just in ritual worship, but throughout the day, meant that they served as powerful shields against the values of the slaveholders and their killing definitions of black humanity. For one thing, along with a sense of the slaves’ personal self-worth as children of an omnipotent God, the spirituals offered them much-needed psychic escape from the work a day world of slavery’s painful and inhumane restrictions and indescribable cruelties. Indeed, “this world is not my home” was a steady theme in the spirituals, one that offered its singer philosophical/transcendental visions of a peaceful, loving realm beyond the one in which they were engaged in herculean labor. Thus, the spirituals indeed served, in the context of bioethics, as an efficacious solution to the mundane or earthly overwork, injustice, and abominable violence known only to the victims or only to those who directly experience it.

Simply put, the Black American slaves contrived and utilized the spirituals as a remedy or a panacea for the emotional, psychological, mental and indeed bodily pain they experienced in the harsh, hostile and insalubrious environment they were forced to live in by both their slave masters and society at large. Thus, the Negro spirituals are indeed fundamentally relevant in a meaningful way to an authentic discourse of bioethics.

In addition to the relevance of the Negro spirituals to bioethics as propounded above, there remains another connectedness which is often overlooked but whose importance compels admiration here. That the spirituals are pregnant with biblical images there can be little doubt, if any. And, a broad definition of bioethics necessarily includes or is emblematic of the spiritual aspect, particularly, if bioethics is maximally defined to embrace an holistic world view and an ontology that embraces all those realities that constitute existence, then the spiritual dimension cannot logically be excluded.

Booker T. Washington, an authority in his own right on the Negro spirituals, in commenting on the spirituals, states in no uncertain terms, that “One of the compensations to the Negro for the hardships of slavery was that he learned during this period of his servitude the meaning of the Christian religion.” (Washington, 1981). But more importantly, according to Washington, “the Christianity that the Negro learned in slavery helped him to endure with resignation and without bitterness the hardships of his condition.” (Washington, 1981). What can be discerned from all this is that the slave singer’s faith, his Christianity acquired or learned during the unwarranted period of his abominable servitude provided him with the much-needed fortitude and the hope for a better world. (Washington, 1981). The Negro Christianity and the slave-singer’s faith are explicitly expressed through the spirituals. All the Negro spirituals portray or abound both in the faith and Christianity of the singers. Thus, by both logical and practical inference and implication, the spirituals do, indeed, serve a bioethical purpose and import given that they help to combat the abominable hardships of the human condition of the anguish of their smitten hearts. Herein lies the relevance of the Negro spirituals to bioethics.

While I have approached the discussion of bioethics in this essay, from a broad dimension or perspective as including but not limited to the spiritual dimension, the environment (e.g., forest, the ocean, seas, rivers, lakes and animals) or from the holistic world view, I must be understood to include cultural embeddedness as well in the discourse on bioethics.

In sum, a careful analysis of the Negro spirituals unveils a relevance of the spirituals to bioethics or a connectedness between the former and the latter.

**Conclusion**

Upon a careful and systematic analysis and evaluation of the term commonly employed namely “Negro spirituals” we are led to the inevitable conclusion that the term is opaque. Consequently, Booker T. Washington’s singular repudiation of that common term and his employment of the substitute term “Plantation Songs” and “Jubilee Songs”, effectively removes much of the common-term’s opacity with which it is fraught.

In this essay however, by means of analytical interpretation, we are able to demonstrate, in no uncertain terms, that the spirituals are, indeed, imbued with philosophical relevance. These much-admired slave songs are replete with the philosophical themes of affirmation of God’s existence and His concomitant ontological attributes of omniscience, omnipotence, and omnipresence. Dominant in the spirituals are the songs’ unequivocal affirmation of the philosophical themes of a Supreme Being, a prime mover who, because of His immannence, is involved in human history as enforcer of universal justice, a liberator of victims from the yoke of evil, a guardian of freedom, and source of hope.

Additionally, in the spirituals the slave singers affirm their unequivocal belief in the Dignity of Man and in the Equality of All Men. Unique to this study is the connection and relevance of the spirituals to bioethics, the latter serving as an effective means for survival.
The Negro slaves’ fundamental philosophical position expressed through the spirituals that God exists and He is the Creator of the World is, by implication and inference, a total repudiation of atheism and agnosticism. And these philosophical ideas have their origins in the indigenous, traditional beliefs of the slaves’ African progenitors, as expressed in the proverbs, myths, and religious ceremonies, et cetera.

References


Book Review

Bus Ride to Justice: The Life and Work of Fred D. Gray

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...what happened in my life as it related to the civil rights movement was and is 'to destroy everything segregated I could find.'

Attorney Fred D. Gray’s aforementioned statement has come to exemplify his life and legal career. Throughout Gray’s early years in Montgomery, Alabama, he felt the sting of racial segregation, degradation, and despair. As a result, he has spent all of his adult and professional life dismantling the abhorrent system of racial segregation in all of its manifestations. The book, Bus Ride to Justice: The Life and Work of Fred D. Gray (2013), has become a welcomed addition to the growing body of literature that examines the tremendous contributions of local African American attorneys who have fought against state sanctioned racism. Until recently, when one probed the history of African American Civil Rights attorneys, one undoubtedly would have read about the formidable attorneys Charles Hamilton Houston and his protégée, the former Supreme Court Justice, The Honorable Thurgood Marshall.

Scholars (Rawn James, Jr.; Genna Rae McNeil, James Conyers, Juan Williams, Michael G. Long, Gilbert King) have written voluminously about these legal giants. What follows is a truncated list of books which investigate the lives and contributions of Houston and Marshall:

2. Groundwork: Charles Hamilton Houston and the Struggle for Civil Rights (2011)

Unfortunately, this elitist approach to studying Civil Rights history has ignored the local attorneys who were the actual change agents within their own cities and states. This
practice has, as a consequence, misled many students of history into believing Houston and Marshall were the only attorneys to adjudicate Civil Rights cases. Recently, however, more scholarship has been produced that exposes the heroic, and oftentimes, dangerous work of local African American lawyers who contested racism, bigotry, and prejudice within their own home fronts. A More Noble Cause: A. P. Tureaud and the Struggle for Civil Rights in Louisiana (2011), studied the legal career of Tureaud. This New Orleans based attorney, who practiced Civil Rights Law from the 1930s to 1972, was, at times, the only African American Attorney in Louisiana. Despite his lonely existence, he succeeded in demolishing the state’s segregation laws.

The Gentle Giant of Dynamite Hill: The Untold Story of Arthur Shores and his Family’s Fight for Civil Rights (2012), has exposed the life and contributions of the tremendous Civil Rights Attorney, Arthur Shores of Birmingham, Alabama. Shores, despite the Ku Klux Klan’s many attempts to murder him and his family, courageously continued to fight against racial injustice until legal segregation was destroyed in Birmingham.

Another recent publication highlighting the importance of local, African American Civil Rights Attorneys is Loren Miller: Civil Rights Attorney and Journalist (2015). Miller, who ultimately became a California State Supreme Court Justice (1967), earned a reputation as a tenacious Civil Rights crusader. Miller utilized both jurisprudence and journalism to dismantle many of California’s discriminatory laws and covenants.

By writing Bus Ride to Justice, Fred D. Gray (2013) joined the pantheon of attorneys who have engaged their legal talents to liberate their hometowns and states from the ravages and vestiges of Jim Crow laws. This deeply reflective and dynamic book has accurately exposed Gray’s role in some of the most significant and historically important events in modern history such as the Montgomery Bus Boycott, the Selma to Montgomery March, and The Tuskegee Syphilis Case. Moreover, his family and personal life have been copiously examined within this text. As a result, the book’s title, Bus Ride to Justice: the Life and Works of Fred D. Grey is misleading.

Generally, in contemporary American society, any reference to a “Bus Ride to Justice” symbolizes the famous Montgomery Bus Boycott. However, this book has explored more than just this historic event. And so the “Bus Ride” connotation has become a metaphor for Attorney Gray’s tremendous life’s experiences.

The 2013 version of this book is revised from the 1995 original publication. In the most recent edition, Gray acknowledged those persons who contributed significantly to the earlier version, but who were deceased by the time of the release of the second issue. In a heartfelt tribute he mentioned the vital impact that his late wife, Bernice Gray, had on the initial publication. He painstakingly acknowledged her contribution to the book and to his life when he said, “Bernice was primarily responsible for the writing of the first edition.” He continued, “She also enabled me to do in life, in the church, and in my profession” (Gray, 2013, p. IX).

In addition to his beloved wife, Gray recognized and validated the support given to him by his late siblings Pearl Daniels, Thomas, and Hugh Gray. He lovingly discussed their contribution to both the 1995 publication of the book and to his life. Finally, he fondly recalled the love, support, and friendship he received from the late Joanne Bibb and Obie Elie. Gray, in this recent edition of the book, revealed the deep sense of loss and pain he felt regarding the passing of his loved ones and friends when he wrote, “All those named above—persons dear to me—transitioned out of my life” (p. X-XI). These passionate insights can be found throughout the book.

This reflective autobiography can actually be divided into the following six parts: 1. Early Life; 2. The Montgomery Bus Boycott; 3. Other Civil Rights Battles; 4. Personal Aspirations and Yearnings; 5. The Syphilis Challenge; 6. Introspections and Challenges.

Early Life
(Chapter 1-The Making of a Lawyer)

Fred Gray, very early in his life, was driven by a strong sense of righteousness and a yearning for fairness. Chapter one of Bus Ride to Justice clearly revealed the foundations of Gray’s tenacity and initial opposition to racism and oppression. In this portion of the book, he discussed his family life, educational experiences, matriculation at Case Western Reserve law school, and establishment of his first law practice in Montgomery, Alabama. However, the author used a unique introduction to the chapter that examined his early life. Gray began this retrospective glimpse into his initial years by revisiting the 1959 Gomillian v. Lightfoot case, which challenged the State of Alabama’s gerrymandering of Tuskegee Institute, Alabama. The chapter’s first sentence tested the mid-20th century notion that African Americans were afraid of legally confronting the white power structure. Moreover, it obliterated the long held view that nearly all African American attorneys were incapable and incompetent. Gray (2013) offered a strongly worded challenge to the status quo when he said, “The nine old men inside were not waiting on me as I walked up the white marble steps of the United States Supreme Court on a warm May morning in 1959.” He declared, “But I was waiting for them, I—and those I represented—had been waiting for several centuries” (p. 3). This illustration of Gray’s resolve established the tone for the rest of the chapter by identifying his determination to confront and destroy racism.

Gray, after substantiating his fearlessness and formidable, introduced the reader to his early family and home life. He revealed the overwhelming love and encouragement he received from his father, mother, and siblings. When he was two years old his father died. Afterwards, Nancy Gray Arms, his mother, worked even harder to ensure that her five children would not only survive, but thrive. Education became the vehicle by which the Gray siblings would succeed. In fact, the older Gray children would have a great influence on their youngest brother. They encouraged him to live spiritually and forthrightly. Gray, after attending the Nashville Christian Institute (high school), returned home to Montgomery to attend Alabama State College (now Alabama State University).

At this point of the chapter, Gray began to describe his angst with segregation. While at Alabama State College, he privately vowed to legally dismantle and destroy the remaining
vestiges of the Confederate South. To this end he wrote, “By my junior year at Alabama State, I understood more fully that everything was completely segregated not only in Montgomery, but throughout the South and;” he concluded, “in many places throughout the nation” (2013, p. 13). This portion of chapter one is very salient because it provides the reader with a keen insight into Gray’s motivations and agitations. These anxieties described by Gray have become the stimuli for his entire legal career. Gray (2013) offered an intriguing glimpse into his thought process when he penned, “I concluded…African Americans were entitled to all the rights provided by the Constitution of the United States of America.” Continuing his diatribe he said, “Therefore, I decided I would become a lawyer” (p. 13).

As the title of the chapter indicates, Gray’s law school experiences are explored. True to the previously stated promise he made to himself, Gray attended law school (Case Western Reserve) and, in 1954, became a lawyer. Moreover, as with all attorneys, then and now, he had to pass the bar examination before he was allowed to practice law. In 1954 Gray passed both the Ohio and Alabama bar examinations, which allowed him to practice law in both states. He decided to practice law in Montgomery, Alabama, in 1954. During this period, he strengthened his relationship with Ms. Bernice Hill, who ultimately became his wife. In addition, he developed alliances with the following major change agents who would provide him with great assistance and support throughout his career: Solomon Seay, E. D. Nixon, Charles Langford, Clifford Durr, Arthur Shores, and Rosa Parks. During the “Movement”, Gray would provide many of these Civil Rights stalwarts with expert legal assistance and representation.

Chapter one of Bus Ride to Justice established Gray’s doggedness and determination to destroy race-based sanctions and restrictions. It exposed the reader to his spirituality and forthrightness and, thus, prepared the reader for Gray’s future challenges discussed in subsequent chapters.

The Montgomery Bus Boycott (Chapter 2-The Bus Protest Begins/Chapter 3- The City’s Get Tough Policy)

Many scholars (Robinson, 1987; Pierce, 2005; Friedman, 2010; Branch, 2013) have identified the Montgomery Bus Boycott as the watershed event that inspired a nationwide protest against this country’s Apartheid system. “Events in Montgomery suggested that black activists, even in the segregated South, could effectively mobilize—and then organize—community resources to fight racial discrimination” (Murrin, Johnson et al., 2008; p. 777). Fred Gray was at the epicenter of this movement. He quickly became the attorney for Rosa Parks, Martin Luther King, Jr., and the Montgomery Improvement Association (MIA). The MIA was the organization that African Americans created in order to coordinate the Bus Boycott. Gray, in addition to being the attorney, became one of the MIA’s agenda setters and gate keepers.

In these chapters, he revealed the African American activism that existed in Montgomery prior to Mrs. Park’s arrest. He also disclosed the lesser known fact that multiple African American women had been arrested on Montgomery’s buses before Parks. Claudette Colvin and Mary Louise Smith were two of the women who had been arrested for refusing to relinquish their bus seats to white people. This chapter uncovered the fact that Parks’ arrest was not a random occurrence. According to Gray (2013), “She was not as meek as many still believe, she was not merely tired from a day’s work, and her arrest was not exactly an accident.” He maintained, “Her arrest was extremely significant because it set the stage for the legal challenge against bus segregation that the local black leadership had declined to make with the Colvin case” (p. 33).

Grays’ legal representation of the MIA, as well as being a boycott strategist, catapulted him into the realm of a Race Man leader. Unfortunately, the book failed to identify his leadership style, despite its comprehensive examination of Gray’s cases and civil rights era struggles. The first major study of African American leadership types was Gunnar Myrdal’s (1944), An American Dilemma. “Myrdal argued that African American leaders dealt with oppression from whites by either accommodating to the racial status quo, or protesting against racially discriminatory policies and practice” (Robertson, 2004: p. 286). Daniel Thompson (1963), a New Orleans-based sociologist, continued the investigation of African American leadership types in the book, The Negro Leadership Class. It was Thompson who identified the Race Man leadership type. According to Thompson, “The race man…insisted that racial segregation of any kind is psychologically harmful, has constantly voiced his protest in literature, music, public utterances, and organizational objectives.” Thompson continued as though he was personally describing Gray, “At all times he expresses a restlessness and declares his impatience with second-class citizenship” (1963; p. 76).

The previously discussed oversight did not diminish the book’s fascinating coverage of Gray’s Montgomery Bus Boycott exploits and coalescences. Throughout chapter two, he discussed his relationship with contemporary icons such as Thurgood Marshall, Adam Clayton Powel, Ralph Abernathy, Rufus Lewis, and Coretta and Martin Luther King, Jr. He provided the readers with “behind the scenes” prospective of the founding of the MIA, and the selection of its leaders. King, Abernathy, Nixon, and Lewis were all selected to prominent positions in the newly formed organization. Gray was also selected to a very prominent position. He posited, “I was chosen to handle the legal work. Whatever King was involved in legally, from then until he left Montgomery, was my responsibility.” Gray celebrated his new role, “I liked that. I was indeed his attorney and continued to serve in that capacity…after he left, when needed” (2013; p. 65).

Within chapters two and three, Gray remembered several vital legal cases that were essential to the success of the boycott. Browder v. Gayle (1956) and State v. Fred D. Grey (1956) were two cases that Gray discussed in this section of the book. He also demonstrated that, despite the retaliations, turmoil, threats, and ever present dangers that existed throughout the boycott, life went on. This was confirmed when, in chapter three, he discussed his wedding to Bernice. The Grays’ wedding was not only a symbol of mutual love and understanding; it was also an affirmation of defiance towards Montgomery’s white power structure. According to Gray, “It was a Protest wedding, that’s what we called it” (Gray, 2013; p. 90). Ultimately, with the expert legal assistance offered by the young attorney, Montgomery’s African American community proved that a unified people could defeat a regressive, oppressive, and well entrenched racist system.
The chapters that comprise this section have detailed Gray's legal career immediately following the Montgomery Bus Boycott (1955-1957). Most readers have not considered Gray's legal efforts after the ending of the momentous boycott in Montgomery, Alabama. The experiences narrated within these chapters have provided an acute understanding of his motivations, provocations, and actions. They also proved that, after the ending of the boycott, Gray continued to advocate on the behalf of African Americans who were unlawfully challenged by America's bigoted and chauvinistic systems.

Chapter four highlighted several court cases that Gray represented after the boycott ended such as Alabama v. L.L. Anderson (1959). However, the Sergeant Wesley Jones Case (1955) exposed the many humiliations suffered by African American lawyers in the 1950s and 60s. In 1955 Gray represented an African American Air Force Sergeant named Wesley Jones. Jones was arrested in Selma, Alabama, after having a confrontation with a white couple. He retained Gray's services, after he was unwarrantedly charged with disorderly conduct. Gray lost his initial legal defense of Jones. However, during the appeal, Frank Massey, Gray's traveling companion, was erroneously arrested for drinking an alcoholic beverage in court. Massey had not consumed any alcohol in court. His arrest was an attempt to intimidate Gray and to discourage him from continuing with the appeal. Of course, Gray was not diverted and the case was dropped.

In 1956 the NAACP was prohibited from operating within the State of Alabama. Chapter five covered Gray's effort to legalize the NAACP within this State. In 1956 he was retained to represent the aforementioned Civil Rights organization. For seven years, Gray pressed forward with the case. Finally, on October 9, 1964, the NAACP was allowed to operate within Alabama.

In Chapter 6 Gray pursued one of his most significant cases since the Montgomery Bus Boycott. Gomillion v. Lightfoot (1957) was the legal case that opposed Macon County Administrators’ attempt to gerrymander the African American voters out of the Tuskegee City boundaries. Gray (2013) remembered when he was hired to represent the Tuskegee Civic Association (TCA), “The Tuskegee Civic Association retained me to have Alabama Act 140 declared unconstitutional and to reestablish the old residential boundaries" (p. 114). Eventually, the U.S. Supreme Court ruled that the gerrymandering of Tuskegee was illegal. Gray recognized the significance of this historic case when he said, "...Gomillion v. Lightfoot is perhaps the most important civil rights case that I have had the privilege of handling.” He submitted, "...I thought from the beginning we would win in spite of overwhelming odds (2013; p. 119).

Gray, in chapter seven, discussed the Eufaula Housing Case (1958). This case involved several African American families that lived in downtown Eufaula, Alabama. This African American community had existed since the 1860s. By 1958 Gray and NAACP Attorney, Constance Baker Motley, had filed the Stephen Tate v. the City of Eufaula lawsuit. The lawsuit attempted to prevent the City of Eufaula from confiscating the homes of African Americans who lived in the Albert Street community.

Later in 1958, Gray's clients were given financial awards with which they were very pleased. What is also significant about this case is that it was adjudicated before Judge George Wallace. Surprisingly, Wallace was a fair magistrate in this trial. However, what is most impressive was the attorney's altruism. "When I started the case, however, I did not know whether I would even be paid because my clients had very little money.” However he reasoned, "But I was willing to accept these cases because the Albert Street Club needed help” (Gray, 2013; 137). Fortunately, Gray was paid for his due diligence. In fact, he enjoyed the largest payday of his young career.

From chapter eight through chapter 10, Gray discussed more lawsuits and cases. He reminisced about defending Martin Luther King, Jr. (1960) against tax evasion charges in Montgomery, Alabama. In addition, he reviewed the Times V. Sullivan case (1960). This landmark case established the malice standard in libel trials.

Moreover, Gray defended Freedom Riders, Sit-In Participants, and Freedom Walkers. In chapter 11, Gray revisited the integration of the University of Alabama and Auburn University, Alabama's two flagship universities. He also recalled the integration efforts involving Montgomery area public schools. In this chapter Gray probed the concept, "with all deliberate speed", as it pertained to integration. In 1955, in conflict with the Brown v. Board (1954) ruling, The United States Supreme Court allowed Southern states to gradually implement integration within public schools. "...Brown II decreed that the process of dismantling illegally segregated school systems should not go into effect immediately; desegregation could, instead move forward with all deliberate speed” (Murrin, Johnson, 2008; p. 776).

The United States Supreme Court, with the Brown II ruling, anticipated the massive state of unpreparedness/unwillingness of the Southern states to implement the initial Brown v. Board ruling. To this end, Gray (2013) made the following observation, “Having made the ruling, the Court failed to carefully and completely spell out how this tremendous change in the social order was to be implemented and enforced by the legislative and executive branches of government” (p. 186). The "All deliberate speed" edict allowed Southern states to establish a stout defense against the integration of public schools and other institutions. "Instead," wrote Gray, "the Court simply declared that a public education should become integrated with all deliberate speed...it gave the South years to evade the intent of the Court's decision" (2013; p. 186). Gray promptly responded to this legal escape hatch by filing lawsuits that forced Alabama to adhere to the original intent of Brown v. Board.
Gray, in chapter 12, challenged the “with all deliberate speed” doctrine by demanding immediate African American voting rights in Selma and throughout Dallas County. During the Selma-to-Montgomery March/Movement (1965), Gray collaborated with Civil Rights heroes such as Amelia Boynton Robinson, John Lewis, Hosea Williams, Bernard Lafayette, C. T. Vivian, et al. Gray, as the legal arm of this movement, was principally responsible for the success of the March 25, 1965 Selma-to-Montgomery March. His efforts began on March 8, 1965, when he filed the *Hosea Williams v. George C. Wallace* suit in federal court. One day earlier, March 7, 1965 thousands of marchers had gathered in Selma, Alabama, to protest the killing of Jimmie Lee Jackson by a Dallas County Sheriff Deputy, and demand voting rights for African Americans. These protesters attempted to march across the Edmund Pettus Bridge and were brutalized by law enforcement officers.

Attorney Gray’s legal maneuverings made it possible for the marchers/human rights advocates to reach Montgomery, Alabama, and present their demands into the lap of Governor George Wallace. Moreover, as Gray recalled, the *Williams v. Wallace* (1965) case “…affirmed the constitutional rights of African Americans, and others, to peaceably assemble, demonstrate, and protest the actions of government.” Gray proudly declared, “…the march from Selma to Montgomery led directly to the Voting Rights Act of 1965” (2013; p. 218).

**Personal Aspirations and Yearnings**  
*(Chapter 14-Fred Gray the Politician/Chapter 15-Fred Gray the Preacher/Chapter 16-The Family)*

In chapters 14, 15, and 16 readers were allowed to glimpse Gray’s political, religious, and personal life. Chapter 14 explored his desire to achieve political prominence, which began in 1966. He initially ran for the Alabama House of Representatives, District 31, Seat 2. This House Seat covered Barbour, Bullock, and Macon counties, areas in which he had practiced law. Unfortunately, the author does not mention the role that the Tuskegee Institute Advancement League (TIAL) played in his initial campaign. During this period, Tuskegee Institute students had begun to protest against racism, promote literacy and voting rights throughout the Alabama Black Belt.

In 1966 nearly 75 African Americans ran for public office in the Black Belt counties. The two prominent candidates were Lucius Amerson, who ran for Sheriff of Macon County, and Fred Gray. Members of the Tuskegee Institute Advancement League were very proactive in voter registration drives, during the 1966 election. In fact, TIAL members had become very involved in the campaigns for Gray and Amerson. His young supporters would often wear plain grey buttons to symbolize their support. Ultimately, Gray lost this election by 600 votes. Sadly, the omission of TIAL from this discussion has contributed to the dearth of information concerning the invaluable impact of this organization on civil and human rights struggles in the South.

In 1970 Tuskegee Institute students were called upon, once more, to support Gray’s political aspirations. “Students were organized and went into all three counties.” As Gray recollected, “…students from Tuskegee Institute were not afraid” (2013; p. 164). With the relentless students’ support, he became a member of the Alabama House of Representatives.

**Bus Ride to Justice** uncovered Fred D. Gray’s spirituality which has helped influence and guide his legal career and civil rights advocacy. It is made clear, in chapter 15, that his devotion to God led him to pursue justice and equality for African Americans, especially in the South. However, as Gray (2013) recalled, many people doubted his ability to be both a Congregationalist Pastor and Civil Rights Attorney, “...no one had ever heard of a preacher also being a lawyer.” He reminisced, “This created a problem for some of our members” (p. 271). Nonetheless, Gray proved his naysayers wrong. From 1957-1973, he pastored the Newtown Church of Christ in Montgomery and practiced law.

Chapter 16 was the most personal section in the book. In this chapter, Gray expressed the deep pain he felt when his wife, Bernice died. The late Bernice Gray had supported her husband’s legal and ministerial careers since 1954. The description of how empty his home felt, after Bernice’s death, was vivid and revealing. The reader was able to feel his tremendous loss when he wrote, “To come home to an empty house without her was more painful than I can describe” (Gray, 2013; p. 279). Fortunately, Gray found another soul mate in Carol Ann Porter. They were married on December 17, 2000.

This portion of the text exposed Gray’s raw emotions and sensitivities. He was shown to be more than just a hard driving attorney. This is an important point because throughout this book, he was portrayed as a relentless crusader. Gray was presented as being one who risked his own life to ensure that African Americans enjoyed first-class U.S. citizenship. In addition, his relationships with larger than life figures such as Dr. Martin Luther King, Jr., Adam Clayton Powell, and Constance Baker Motley might have been intimidating to some. However, in chapter 16, readers were able to see him as they may sometimes be: vulnerable, loving, and human.

**The Syphilis Challenge**  
*(Chapter 18-The U. S. Public Health Syphilis Study at Tuskegee)*

From 1932 to 1972 the United States Government conducted clandestine medical experiments on unsuspecting African Americans in Macon County, Alabama. The U. S. Public Health Syphilis Study at Tuskegee adversely impacted over 600 African American men. “The medical intent,” said Gray, “was to observe the effects of untreated syphilis” (2013; p. 295). As devilishly onerous as this government sponsored assault on African American men/people might have been, it was one of many similarly based “experiments” that only used African Americans as subjects of inquiry. According to the author of the book *Medical Apartheid: The Dark History of Medical Experimentation on Black People from Colonial Times to the Present* (2006), Harriet Washington, “Many studies used only or principally African Americans, although some included a smattering of Hispanics.” She continued, “Some research studies specifically excluded white subjects according to the terms of their official protocol” (p. 6).
African American women were often the victims of unsolicited medical procedures. Some impoverished African American women were threatened with the termination of their welfare benefits if they did not consent to a hysterectomy. To this end Lisa Wade (2011) suggested, “U.S. women of color have historically been the victims of forced sterilization” (Sterilization of Women of Color, para. 1). Sterilization was only one of many types of experimentation performed on innocent African American victims.

In Lyles Station, Indiana (1931), African American children were the subjects of a vicious medical experiment. The children’s parents were tricked into agreeing to have their kids treated for ringworms. However, the U.S. Government used these children as guinea pigs in high dosage radiation tests. As a result of which, Vertus Hardiman, a victim of the government’s subterfuge, was injured and disfigured. Hardiman received a very intense dosage of radiation which burned a hole into his head. He has recently become the subject of a documentary entitled, Hole in the Head: A Life Revealed (2011).

Each experiment on unsuspecting African Americans was egregious and immoral. These illicit tests were conducted from the 18th through the 20th centuries. What has separated the United States’ Public Health Syphilis Study at Tuskegee from the other medical violations perpetrated against African Americans was Fred D. Gray. Shortly after Gray began representing the victims, he reached the following conclusions:

1. The U.S. Government violated the victims’ constitutional rights,
2. The U.S. Government did not inform the victims that they had syphilis,
3. The U.S. Government failed to treat the victims,
4. The U.S. Government misled the victims to believe that they were being properly treated for a fictitious disease,
5. The U.S. Government did not secure the legal permission of the victims to participate in the study,
6. The TSS was racially motivated and discriminatory.

Ultimately, Gray successfully sued the United States Government and won financial compensation for the living victims and the heirs of those who were deceased. During this case, Attorney Gray demonstrated the same fearlessness and tenacity that buttressed his abhorrence of segregation and inequality in Montgomery and Selma. In addition, the case exemplified his willingness to represent the underrepresented and give a voice to the voiceless.

From chapter 19 through 24, Gray reflected on his triumphs and travails. He reminisced about people who had both positive and negative impact on his life and legal career. He also provided sagacious advice for young attorneys who are interested in pursuing Civil Rights Law. In chapters 19 and 20, Gray discussed his unsuccessful bid to become a United States District Judge for the Middle District of Alabama. These chapters revealed his disappointment and confusion concerning the many challenges he encountered from unexpected sources. He bemoaned getting a negative review from Morris Dees, the founder of the Southern Poverty Law Center. As Gray asserted, Dees’ opposition was surprising and hurtful; “The greatest disappointment, which was totally unexpected, was Morris Dees’ appearance and testimony in opposition to my appointment” (2013; p. 306). In addition to Dees, Senator Howell Helbin also withdrew his support of Gray’s nomination. Eventually, with Gray’s support, Myron Thompson would be appointed to the aforementioned position. Not receiving the judgeship was only a temporary setback for Gray. He and his late wife, Bernice, built a beautiful estate in Tuskegee, Alabama, and made lucrative real-estate investments. Moreover, his law practice, which included his sons Fred, Jr., and Stanley, had begun to expand.

Of course one would expect an experienced and successful attorney, such as Fred Gray, to train, mentor, and advise young attorneys. Chapter 21 clearly identified the fact that his passion was working with young lawyers. Specifically, he challenged young barristers to find solutions to segregation, inequality, and racism in all of its manifestations. “I call upon the entire community, and particularly our young lawyers, to challenge themselves to solve these problems...” (Gray, 2013; p. 327). Furthermore, Gray has continued to confront racial inequalities in all of its forms, including education. Chapter 22 chronicled his claim that Alabama State and Alabama A & M Universities had been historically underfunded by the State of Alabama. In Knight v. Alabama (1984), Gray proved that there were vestiges of segregation and unequal funding in this state’s institutions. Furthermore, White v. Alabama (1993) challenged Alabama’s repressive appellate court elections practices. According to Gray (2013), “...the existing appellate court election process violated the Voting Rights Act” (p. 349). Eventually, the State of Alabama would create a more equitable appellate elections procedure.

In the final chapters of the book (22 and 23), Gray both celebrated his mentees and paid homage to his mentors. In chapter 22 he glowingly mentioned the positive impact that he had on the following attorneys: Donald Watkins, Solomon Seay, and Terry Davis. A prideful Gray asserted, “It is indeed a good experience to have worked with lawyers who are...helping to change the landscape of this country” (Gray, 2013; p. 346). Moreover, in chapter 23, he also acknowledged the dynamic influence that Arthur Shores, Clifford Durr, Judge Frank Johnson, Jr., and Governor George Wallace had on his life and legal career. Wallace’s influence on Gray, it turned out, motivated the latter to destroy everything segregated he could find. To this end Gray wrote, “I filed many of the cases discussed in this book when he was governor” (2013; p. 359).
Book Review

**Conclusion**

*Bus Ride to Justice: The Life and Works of Fred D. Gray* revealed the tenacity, persistence, and angst of the courageous and dynamic attorney. This book successfully demonstrated how a locally based, race man leader confronted the most powerful forces in the State of Alabama and secured the Civil and Human Rights of its African American citizens. *Bus Ride To Justice* also has deconstructed the practice of only highlighting civil rights era legal giants such as former Supreme Court Justice, Thurgood Marshall and Charles Hamilton Houston. What is often lost in this approach is that real change came from the agitation of local attorneys and change agents, such as Fred Gray. In fact, Gray and others like him, contributed mightily to the African American struggle to obtain fairness and equality.

*Bus Ride to Justice* is an invaluable firsthand account of Gray’s legal career, personal, and family life. It has allowed the reader to understand and appreciate the dedication, determination, and discipline the movement for human and civil rights demanded from its adherents. It also must be acknowledged that most scholarly examinations of this period of American history have focused on the marches and protests, which immeasurably involved thousands of people. However, *Bus Ride To Justice* revealed that Gray was often the only attorney, or one of only a few lawyers, filing a lawsuit or defending a client. As a result, this book has contributed inestimably to the study of grassroots/local attorneys who helped secure a semblance of racial equality in their divided communities.

References


The Journal of Healthcare, Science and the Humanities
June 2014

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.

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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.
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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.

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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.

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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.

IV. Style Requirements


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
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Each manuscript must be subdivided into relevant sections as discussed above. Sections may be further subdivided to enhance the discussion or for other editorial reasons. Major sections should use Level 1 headings. Subsections should use headings for Levels 2 through 4. Directions for formatting Headings follow:

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