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ARTICLES

Research Challenges and Bioethics Responsibilities in the Aftermath of the Presidential Apology to the Survivors of the U. S. Public Health Services Syphilis Study at Tuskegee

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In 1997 President Clinton apologized to the survivors of the U.S. Public Health Service Syphilis Study. Since then, two of his recommendations have received little attention. First, he emphasized the need to remember the shameful past so we can build a better future for racial/ethnic minority populations. Second, he directed the creation in partnership with higher education to prepare training materials that would instruct biomedical researchers on the application of ethical principles to research with racial/ethnic minority populations. This article proposes the inclusion of these issues in the implementation of the Affordable Care Act. It asks, What is the right or good thing to do? What are our obligations to one another? Two challenges are examined: (a) Conducting research with African Americans without knowledge of bioethics specific to this population, and (b) the ethical dilemma of conducting research that does not adequately take into account the diversity within the Black population that is a contributing factor in health disparities. Training and policy recommendations responsive to President Clinton's Apology are presented.

Keywords: Presidential Apology, Affordable Care Act, population health ethics, research ethics training

The eight men who are survivors of the Syphilis Study at Tuskegee are a living link to a time not so very long ago that many Americans would prefer not to remember, but we dare not forget. It was a time when our nation failed to live up to its ideals, when our nation broke the trust with our people

that is the very foundation of our democracy. It is not only in remembering that shameful past that we can make amends and repair our nation, but it is in remembering that past that we can build a better present and a better future. . . . We commit to strengthen researchers' training in bioethics. . . . So I am directing Secretary Shalala to work in partnership with higher education to prepare training materials for medical researchers. They will be available in a year. They will help researchers build on core ethical principles of respect for individuals, justice and informed consent, and advise them on how to use these principles effectively in diverse populations. . . . To increase and broaden our understanding of ethical issues and clinical research, we commit to providing postgraduate fellowships to train bioethicists especially among African Americans and other minority groups. HHS will offer these fellowships beginning in September of 1998 to promising students enrolled in bioethics graduate programs. (Clinton, 1997)

In 1997 former President Clinton on behalf of the federal government issued an apology to the male survivors of the Tuskegee Study of Untreated Syphilis in the Negro Male (Chelala, 1997; Mitchell, 1997) and their families. This long overdue apology for unethical treatment of African American men in a study conducted by the federal government was both a historic moment and a moment of hope for change in the accountability of researchers working with African American participants (Harter, Stephens, & Japp, 2000). Clinton called for us not only to remember the Tuskegee Study, which began in 1932 and only ended in 1972, but to learn from its ethical failures in order to build a better present and future (Chelala, 1997). In his role as president, he directed then secretary of Health and Human Services Shalala to develop ethics training materials that would educate biomedical researchers about core ethical principles to prevent similar research abuses from occurring in African American populations. In his speech he focused in on "principles of respect for individuals, justice and informed consent" and advice on how to use these principles effectively in racial/ethnic minority populations (Clinton, 1997). The year 2012 represents the 15th anniversary of President Clinton's call for creating a better present and future, an appropriate time to reflect on whether we have met his call for change.

In the last decade, scholarly efforts to examine the legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male (the study's formal name) have focused on documenting the rates of participation in research by African Americans and their mistrust of the research enterprise (see Mays, Coles & Cochran, 2012; Buchbinder et al., 2003; Katz et al., 2008; Kibler, Vigil-Otero, Sarpong, Lally, & Mayer, 2012; Mays, 2011; Moutsiakis, & Chin, 2007; Newman et al., 2006). Much of this investigation was a response to the reported difficulties of clinical researchers with recruiting and participation of African Americans for human studies, particularly HIV-related clinical and behavioral trials (Buchbinder et al., 2003; Kibler et al., 2012; Mays, 2011; Slomka, Ratliff, McCurdy, Timpson, & Williams, 2008). This focus on mistrust and clinical trial participation has distracted from efforts to develop core bioethical principles for health research specific to African Americans. This, in turn, has slowed efforts to develop science-based trainings that address the ethical dilemmas specific to research with Black Americans (Mays, 2001). Starting with the leadership of then Health and Human Services Secretary Shalala, National Institutes of Health (NIH) did commission through its T15 grant mechanisms course development of research ethics, but little was focused specifically on African Americans. Although many of the T15 courses were developed and some publically shared (Office of Extramural Research, n.d.), no NIH policy or consensus developed from this work that provided guidance specifically on ethical approaches for working with African Americans. It is the case that President Clinton's call for change has elicited only a partial response.

The goal of this article is to refocus discussions about the legacy of the U.S. Public Health Service Syphilis Study at Tuskegee away from blaming African Americans for their mistrust of the research system and toward developing a science-based bioethics for conducting research in African Americans populations. This article examines the challenges faced in research endeavors as a function of not having a bioethics health research guide for working with African American populations.

In the face of the tremendous health disparities that African Americans experience, research efforts that are efficacious and provide solutions need to be fast-tracked to reduce premature loss of life (Satcher et al., 2005; Woolf, Johnson, Fryer, Rust, & Satcher, 2004). In an article by Satcher and colleagues examining Black/White mortality disparities for 1991 to 2000, age-adjusted mortality rates for White men and women were one fourth to almost one third lower compared to African American men and women (Woolf, Krist, Johnson, & Stenborg, 2005). They estimate that if during this period the two racial/ethnic groups were comparable it would have prevented the deaths of 886,202 Black Americans. They estimate that if Black/White mortality disparities did not exist it would save 83,570 Black Americans each year (Satcher et al., 2005). This same racial/ethnic pattern of health disparities is evidenced in proportionally greater number of cases of HIV, diabetes, or cardiovascular disease that are adding to the morbidity in Black Americans (Karlman, Merkin, Crimmins, & Seeman, 2010; Macinko & Elo, 2009). The greatest disparities exist in the receipt of health care services. The IOM Report, as well as a number of reviews (Abreu, 1999; Canto et al., 2000; Escarce, Epstein, Colby, & Schwartz, 1993; Franks, May, Wenger, Blount, & Eaker, 1993; Giacomini, 1996; Gomes & McGuire, 2001; Johnson, Lee, Cook, Rouan, & Goldman, 1993; Mayberry, Mili, & Ofili, 2000; Nelson, 2002; E. D. Peterson, Wright, Daley, & Thibault, 1994; E. D. Peterson, Shaw, DeLong, Pryor, Califf, & Mark, 1997; Schulman et al., 1999; Smedley, Stith, & Nelson, 2003; Van Ryn, 2000) have cited instances of differences in services. A study of Medicare beneficiaries' utilization data for 1986 found that African Americans were less likely than Whites to receive 23 different services, including such procedures as cardiac surgery. The more advanced, invasive, or expensive the technology, the less likely it was used in the care of African Americans. More recent studies demonstrate that compared to Whites, African Americans who come to emergency rooms with complaints of chest pain are less likely to be admitted to the hospital, and are less likely to receive care in coronary care unit, thrombolytic therapy, coronary angiography, or bypass surgery. They are more likely to be sent home and told to monitor their conditions and come back if the symptoms continue. They receive less aggressive care and intervention to reduce morbidity and mortality. Although research was able to count and document differences in inequities; to close the gap, additional research is needed to understand more the context of the behavior and the social determinants of the inequities.

Research is needed to understand the mechanisms by which racial health disparities persistently occur. But before such research can begin, researchers who are unfamiliar with the cultural and contextual contributions that are embodied in African American population-level health inequities would greatly benefit from training that could increase their research skills for increasing the participation of adequate numbers of African American in research. Study results are statistically valid in specific populations only if adequate numbers of subjects are enrolled. Given the severity of health disparities experienced by Black Americans, failing to equip oneself with adequate training to ensure that African American participation in research may be as unethical as allowing African Americans to participate in studies that will not result in findings for their specific racial/ethnic group. Even when African Americans participate in a research study, if

analyses are not conducted due to inability to power such studies it raises equity issues of population benefits for the African American community in participating in research activities. One pathway for better research outcomes in the recruitment and participation of African Americans in biomedical and behavioral research may be through culturally specific bioethical training of investigators that equips them with skills to design research that will attract and retain African Americans. There are two questions that are the domain of bioethics that, although challenging, can serve in developing guidelines for working with racial/ethnic minority populations: What is the right or good thing to do? What are our obligations to one another?

CHALLENGE 1: THE CONDUCT OF RESEARCH IN AFRICAN AMERICAN POPULATIONS WITHOUT BIOETHICS HEALTH RESEARCH TRAINING SPECIFIC TO AFRICAN AMERICANS

Each of us who engages in research funded by the federal government and increasingly other entities such as foundations are required to complete research ethics training. One of the major instruments for this training is the Collaborative Institutional Training Initiative (CITI), which began in 2000 and has flourished as a source for research ethics training (CITI, n.d.). This proliferation of attention to research ethics training is one of the impacts of President Clinton's 1997 Apology.

In this CITI training, we learn some of the facts such as who, when, where, and what happened in Tuskegee but little of the broader contextual bioethical issues. The training fails to instruct how the metaphor of this event is not really over for some African Americans who, as a result of health disparities, poverty, and other societal conditions, enter research studies as a way to access unaffordable tests or care, receive incentives, or access a resource for themselves or family that normally would be beyond their means such as school-based testing for a child or retina scans to check diabetes status. The content and message of the training is that an abusive incident has left African Americans distrustful of medical research. The training says little about how the Tuskegee Study robbed the African American community of longer lives and maybe even different legacies for the men who died from tertiary syphilis.

Little is learned about the stigma experienced by the generations of families of the survivors described in the Wimberly (2012) article in this issue, or the betrayal suffered by undocumented Latinos who were able to participate in research studies but not be eligible based on the 2010 Affordable Care Act for the population-level health benefits that were developed from those research studies because of their undocumented status described by Carcari Stone and Avila (2012) in this issue. The training never underscores the underlying message of the Tuskegee Study: that the abusive treatment of the African American men conveyed to Black America that White America did not value the lives of these men beyond their use as research subjects and as a vehicle for data collection for scientific publications. The training ignores the fact that Black America sees in the disparities of the current health care system the type of mortality disparities described by Satcher and his colleagues (Satcher et al., 2005; Woolf et al., 2005).

For those who take the CITI training, the Tuskegee Study is a historical event from the long ago past. It is true that the Syphilis Study started 80 years ago, has been stopped for 40 years, and does not currently exist. However, there is little in the training that helps research investigators accomplish the goals of respect and justice that Clinton calls for in his apology (Carmack, Bates, & Harter, 2008). It is in the not knowing that, despite the ending of the Syphilis Study,

its replacement exists in the form of the health care treatment bias described in the Institute of Medicine (IOM) *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* report (Smedley et al., 2003). It is hoped that the articles in this special issue will help researchers have a greater appreciation of the types of ethical violations that fail to employ culturally specific research designs to address respect and justice at the individual and population levels.

In the IOM's *Unequal Treatment* report, we learned that even when insurance status, income, age, and severity of conditions are comparable, health care is not (Nelson, 2002; Smedley et al., 2003). We learned that differences in health care for racial/ethnic minority groups occur as a function of their economic and social status vulnerability that persists within a broader historic and contemporary context of inequality fueled by prejudice, bias, racial/ethnic discrimination, and stereotyping (Nelson, 2002). The very depth of the inequity in health disparities in the African American community coupled with the persistence of nonminority researchers who continue to be funded despite failing to recruit and retain African Americans is a part of the continuing neglect of equal benefit in the research and evidenced-based treatment process. The IOM *Unequal Treatment* report indicated that one solution to the disparities in health was that treatment should be practiced based on the best available science (Nelson, 2002). Yet when research fails to enroll minorities sufficiently in studies to have power to detect racial/ethnic differences, then solutions to health disparities in health care are difficult, if not impossible.

In their review of the literature about evidenced-based mental health treatments for racial/ethnic minority youth, Huey and Polo (2008) found "probably efficacious" or "possibly efficacious" but no "well-established" treatments for anxiety-related problems, attention-deficit/hyperactivity disorder, depression, conduct problems, substance use problems, trauma-related syndromes, and other clinical problems. As Huey and Polo pointed out in their discussion, the sample sizes of many of the youth treatment studies often may not have been sufficient to test true differences. Although studies may indicate findings of no difference in the treatment approaches, no difference does not necessarily indicate group equivalence; it may really reflect a lack of adequate statistical power to detect the difference. Huey and Polo explained that studies intended to test Treatment \times Ethnicity interaction effects are often underpowered, which decreases the likelihood of detecting moderator effects. To detect an interaction effect if ethnicity is really a moderator in the treatment process requires much larger sample sizes (Huey & Polo, 2008) than are often collected. Therefore, in order to provide equal health benefits to racial/ethnic minority's demands that they be present in sufficient numbers to detect treatment differences that are related to race/ethnicity and social status.

Although the Syphilis Study was stopped 40 years ago as of 2012, the legacy of unequal benefit from research continues unabated. Our current bioethics research training fails to equip researchers to understand how well-meaning research, conditions of health care, and health policies are the modern-day manifestation of the Syphilis Study at Tuskegee. The real legacy of the Syphilis Study may be the persistence of societal norms that maintain the vulnerability of particular racial/ethnic minority populations—norms that that allowed the Syphilis Study to move to death as the variable of interest. Where were the African American principal investigators then? Unfortunately a recent study of the Principal Investigatorship of NIH grants raises the same question now (Working Group on Diversity in the Biomedical Research Workforce, 2012). In a recent analysis of the review and award process of NIH grants no matter the type of grant program or mechanism, African Americans were the least likely of all racial/ethnic groups to receive research awards (Ginther et al., 2011).

The U.S. Public Health Service Syphilis Study began as well intentioned and lost its way. It moved from an outcome of searching for ways to save lives to studying the path to the end of life at the expense of African American men. This continues to happen today as investigators competing for a very small number of funded NIH applications submit proposals to which they already know the answers, as they have done this same research in other populations, other context or age groups. It is not really about making a difference in the lives of African Americans but about staying funded. Risky or complicated, high-risk, high-impact grant opportunities are infrequent, and as long as review committees lack senior, well-funded African Americans in sufficient numbers as part of review panels, there is less chance of high-risk, high-impact studies of African Americans being funded in this tight funding climate. It raises yet again the fundamental biomedical ethical questions: What is the right or good thing to do? What are our obligations to one another?

There have been a number of African Americans professionals and others who have argued that it is a wrong assumption to believe that we all share the same ethical values in America (Banner, 1992; Flack & Pellegrino, 1992; Gbadegesin, 2007; Prograis & Pellegrino, 2007; Randell, 2012). Rather, our experiences as filtered by race/ethnicity, culture, gender, and our history in this country shape our perspectives on some of the basic and essential areas of bioethics such as personhood; bodily integrity in how we handle body parts, tissues, fluids, and genetic information; our moral compasses; and even how we define wellness, or a long, fulfilling, and useful life (Bowman, 1992; Branson, 1992; Dula, 1992, 2007; Harris, 1992; Pellegrino, 1992; Peniston, 2007; L. M. Peterson, 1992; Thomas, 1992; Wiredu 1992a, 1992b). Also there is no monolithic African American view of biomedical ethics because of the rich diversity that exists within African, African American, and other subgroups that make up the Black population in the United States (Peniston, 2007; Wiredu, 1992a, 1992b). So even in the constructing of a guide to African American bioethics, it is necessary to be either exclusive of who it addresses within the Black population or inclusive to address the ethnic diversity of Black Americans.

One reason that research bioethics informed by African American perspectives becomes so important and necessary is that there are not sufficient African American research scientists distributed around the country who can ensure adequate protections. It is therefore a greater imperative that bioethics training for the general population of researchers incorporates these perspectives. As long as we are all certified as competent to conduct research on African American but without adequate training, then we are continuing down an unethical path.

Before we can train others about African American bioethics it is important to provide a population-level context that is broader than individual consent and individual reparations but is focused on the deeper legacy of the U.S. Public Health Service Syphilis Study at Tuskegee. For the White researcher, the legacy is that of mistrust that African Americans have about not participating in their research. For African Americans, the legacy is being as vulnerable today as when the actual study took place. If African Americans value as an aspect of their racial/ethnic identity their connectedness to other African Americans, including those who lived in the past and were wronged historically, research participation and its outcomes is not just about the consent of the individual but issues are raised that the actions of one have implications for the welfare of others. So until we can strongly convey that African American bioethics is not just about the rights and wrongs of an individual but that every wronged person regardless of when the wrong occurred impacts the legacy of the future generation, we will not get the teaching of bioethics right.

CHALLENGE 2: CULTURE AND SUBPOPULATION DIFFERENCES IN AFRICAN AMERICANS AS A PART OF ETHICAL RESPONSIBILITY IN THE ANALYSES OF DATA

In conducting research within the Black population in contrast to other racial ethnic groups, less attention is paid to subpopulation differences. Yet data accumulated over a period of years have shown us that culture and racial/ethnic are important in accounting for health attitudes, behaviors, and approaches to treatment. It has become standard practice to assess subpopulations differences within Asian and Other Pacific Islanders and Latinos and to ask Native Americans if they have a tribal affiliation. Yet researchers working within Black populations tend to classify all individuals as Black or African American. In rare cases, researchers record whether Black research participants are U.S.- or foreign-born. Not knowing about ethnic diversity within the Black population can amplify health disparities; this was seen in the case of a publicity campaign designed to inform Californians about a new state law that established the right to a language interpreter in medical settings.

A well-regarded foundation in California funded public campaigns in specific languages to ensure that the diverse populations of California were informed of the right to interpreters in medical care. However, no campaign was launched in languages specific to Black immigrant populations. Yet California is second only to New York in the number and diversity of Blacks who immigrate to the state, and particularly to Los Angeles, where Africans, Haitians, Belizeans, Dominicans, and others with French, African languages, and others can be found. More than one fourth of the Black populations of Boston, New York, and Miami are foreign born. The number of foreign-born Blacks in the United States is significant. In 2005, nearly two thirds of the 2.8 million foreign-born Blacks in the United States were born in the Caribbean or some other Latin American country; one third were born in Africa; and the remaining small percentage come from Canada, Europe, and even Cuba.

In the last decade, as a result of the National Survey of American Life (Institute for Social Research, 2012), we have learned how profoundly important the differences are between Caribbean Blacks and African Americans in the United States and the differences that being U.S. born versus foreign born are in mental and physical health outcomes (Griffith, Johnson, Zhang, Neighbors, & Jackson, 2011; Hammond et al., 2011; Williams et al., 2012). Yet we continue to read studies in which questions of nativity and subpopulation identification are ignored in research on Black Americans. This happens because there continues to be a reliance on the minimum standards in both the collection and classification of data on race and ethnicity in researching Black populations (Mays, Ponce, Washington, & Cochran, 2003).

At a gross level of racial classification, a person is Black or African American. Yet the cultural habits, behaviors, exposures, and ethnic subpopulation origins of Southern Blacks with their African origins can be quite different than those in New England where they may be Cape Verdeans from West Africa and influenced by the Portuguese, or those in Southern California, where they may be of Egyptian origin. In my own case, though I have lived in California for many years, I am very clear that not only am I an African American but I am a Southern African American, as my parents were both from the South and were a part of the big migration from the South to Chicago in search of work. Many things for me that were shaped by my Southern roots: the foods that I ate from childhood through my early adulthood; about my interconnectedness to other African Americans who were part of a migration; or my sense of responsibilities around

my privileged education and occupational status that come from knowledge of the sacrifices of others for my civil rights. When a Black in America is classified in research studies purely by race without some of these other important characteristics, science has failed at capturing the nuanced data that are often key to understanding the role of social determinants in health disparities.

The Populations subcommittee of the National Committee on Vital and Health Statistics, a federal advisory committee which produced reports and letters to the secretary of Health and Human Services about the classification of race and ethnicity (NCVHS, 2005). There was encouragement for the federal government to produce data reports that go beyond the reporting of the minimum five race categories of Black or African American, White, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander, and to report on subgroups when possible (i.e., Puerto Rican, Mexican American, Cuban). Information about Black subgroup differences is critical for efficacious interventions, according to theories on social determinants of health disparities. Given the growing numbers of foreign-born Blacks and the diversity of origin among African Americans, it is critical that health researchers identify subgroup differences in racial groups. Developing tools to educate researchers about the need to understand and search for evidence about subgroup differences is an appropriate response to the questions: What is the right or good thing to do? What are our obligations to one another? Clinton promised survivors a better educated researcher as a means to prevent research abuses, but we have lacked leadership in what the education should be. Too often, the legacy of the Syphilis Study has been defined through the lens of White researchers who have had problems with recruiting and retaining Black Americans in the research enterprise.

THE FUTURE: THE TUSKEGEE LEGACY REDEFINED TO BENEFIT PEOPLE NOT RESEARCH

It is time that we refocus the legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male by not letting its primary legacy be that of White researchers telling America how mistrustful Black Americans are about participating in their research, as if that is a bad thing (Mays, 2011; Katz, et al., 2008; Newman et al., 2006). The legacy should not be the numerous studies of how to get African Americans to participate in research (see Mays, Coles, & Cochran, 2012, in this issue). If there were many more Black researchers, creativity born of collaboration with Black communities would be a part of the dialogue about strategies to increase participation of African Americans in studies. If more racial/ethnic minority scientists were majority members on the review panels that fund research studies, successful methods that engage and retain racial/ethnic minorities in studies would be more prevalent. The spending of precious research dollars on how to address mistrust in nonminority researchers is not advancing research but rather serving as remedial education as do-over attempts at the same study question in the hope of getting it right (Mays, 2011). Researchers without training or experience in community-engaged research—researchers who have never teamed with racial/ethnic minority colleagues or community-based organization CEOs as equal research collaborators—should receive continuing education mandated by their university's Institutional Review Board in this area, even if they are senior in their careers. Despite Clinton's call for the federal government to remedy this lack of education, a majority of researchers lack sufficient knowledge of the intricacies of

racial/ethnic minority populations, particularly African Americans, to conduct research that is not only significant in its findings but that is on point with the experiences of the community.

Another approach is to refocus the legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male to be a legacy of honor and lessons to be learned. First, let us as a nation come to learn about the scientific contributions that the untreated men in the study taught us that help to save the lives of others every day (Mays, 2011). Let us tell the scientific legacy of the study of untreated syphilis in 399 untreated Negro men so that the families of the survivors of these men have their legacy of honor to share with their children and the world that has stigmatized them (Elaine, 2004). We have yet to publicly share the legacy that those who are no longer here left that makes the world a healthier place. (The last study participant died in January 2004. The last widow died in January 2009). A book was published about a Black woman, Henrietta Lacks, whose tumor cells were taken without her permission but yet changed medicine for the better (Skloot, 2010). We are now learning about Henrietta Lacks and the ways in which her contribution, despite being taken without permission, has kept many others alive and changed medicine.

We should tell the human stories of those men who were in the Syphilis Study at Tuskegee, to immortalize each and every one of the 399 individuals as a way to make their inhuman sacrifice compel today's researcher to be more humane. It is important that as a part of the legacy of the Syphilis Study, America and the world know the human side of the men who gave their lives under the banner of science. They are heroes much like those who in war give their lives to protect us. In a very similar way these men gave their lives so that others could medically benefit. Yet unlike the veterans of war we do not honor them through making them visible; instead, we spend more time making the experiment visible and the men invisible. Even when we talk about the study we call it the Syphilis Study and leave out the words "untreated Negro male." Leaving out these words dehumanizes the experiment, making it more difficult for America to internalize the humanity of each of the 399 African American men who were untreated for syphilis. Leaving out the men also makes it easier for it to happen again in some other form. It may take us further in our efforts to make this study have the legacy of changing the behavior of researchers and establishing a set of bioethics guidelines for research if we understood in human terms what was lost in the name of science. Each man who participated in the study is a story, a connectedness back not just to the African American race but the human race, for each of those men left a scientific legacy and also a human legacy. In talking with the families of the "untreated Negro males," I clearly understood that their stories should be a part of the legacy so that we know next time that subjects lives matter and that we must value the lives of all. What are our obligations to each other? One of them is to honor the lives of those who gave theirs on behalf of science by making their humanity come alive through their stories as told by their survivors and through historical documents so that the unethical behaviors of Tuskegee do not happen again. Leadership by the federal government through NIH could accomplish this goal by funding from the National Library of Medicine, which funds historical health books that contribute knowledge to biomedical public health efforts. In this issue, the ways in which this study continues to impact the family survivors of the men are discussed in the Wimberly article as well as the contribution of Mrs. Head, who is a survivor. So clearly our work is not done in addressing the legacy of the Syphilis Study.

The NIH is in the best position to advance the promises of President Clinton to educate researchers to ensure that what happened 80 years ago does not happen again. At the same time, it is also those committees that advise the president of the United States, the White House Office

on Science and Technology Policy, and the Presidential Commission for Bioethics that can play a role in changing the required knowledge base of U.S. researchers.

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REFERENCES

- Abreu, J. M. (1999). Conscious and nonconscious African American stereotypes: Impact on first impression and diagnostic ratings by therapists. *Journal of Consulting and Clinical Psychology, 67*, 387–393.
- Banner, W. A. (1992). Is there an African American perspective on biomedical ethics? In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 188–192). Washington, DC: Georgetown University.
- Bowman, J. E. (1992). The plight of poor African Americans: Public policy on sickle hemoglobins and AIDS. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 173–187). Washington, DC: Georgetown University.
- Branson, H. (1992). Africa, African-American, and the origins of a universal ethic. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 1–10). Washington, DC: Georgetown University Press.
- Buchbinder, S. P., Metch, B., Holte, S. E., Scheer, S., Coletti, A., & Vittinghoff, E. Determinants of enrollment in a preventive HIV vaccine trial: Hypothetical versus actual willingness and barriers to participation. *Journal of Acquired Immune Deficiency Syndromes, 36*, 604–612.
- Cacari-Stone, L., & Avila, M. (2012). Rethinking research ethics for Latinos: The policy paradox of health reform and the role of social justice. *Ethics and Behavior, 22*, 445–460.
- Canto, J. G., Allison, J. J., Kiefe, C. I., Fincher, C., Farmer, R., Sekar, P., . . . Weissman, N. W. (2000). Relation of race and sex to the use of reperfusion therapy in Medicare beneficiaries with acute myocardial infarction. *New England Journal of Medicine, 342*, 1094–1100.
- Carmack, H. J., Bates, B. R., & Harter, L. M. (2008). Narrative constructions of health care issues and policies: The case of President Clinton's apology-by-proxy for the Tuskegee syphilis experiment. *Medical Humanities, 29*, 89–109.
- Chelala, C. (1997). Clinton apologizes to the survivors of Tuskegee. *The Lancet, 349*, 1529.
- Clinton, W. J. (1997, May 16). *Remarks by the president in apology for study done in Tuskegee* [Press release]. Washington, DC: Office of the Press Secretary, the White House. Available from <http://clinton4.nara.gov/textonly/New/Remarks/Fri/19970516-898.html>
- Collaborative Institutional Training Initiative. (n.d.). About the Collaborative Institutional Training Initiative (CITI). Retrieved from <https://www.citiprogram.org/aboutus.asp>
- Dula, A. (1992). Yes, there are African American perspectives on bioethics. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 193–197). Washington, DC: Georgetown University.
- Dula, A. (2007). Whitewashing Black health: Lies, deceptions, assumptions and assertions-and the disparities continue. In L. Prograis & E. D. Pellegrino (Eds.), *African American Bioethics: Culture, race and identity* (pp. 47–66). Washington, DC: Georgetown University Press.
- Elaine, P. C. (2004). Cultural and ethical issues in working with culturally diverse patients, and their families: The use of the culturagram to promote cultural competent practice in health care settings. *Social Work in Health Care, 39*, 249–262.
- Escarce, J. J., Epstein, K. R., Colby, D. C., & Schwartz, J. S. (1993). Racial differences in the elderly's use of medical procedures and diagnostic tests. *American Journal of Public Health, 83*, 948–954.

- Flack, H. E., & Pellegrino, E. D. (1992). *African-American perspectives on biomedical ethics*. Washington, DC: Georgetown University Press.
- Franks, A. L., May, D. S., Wenger, N. K., Blount, S. B., & Eaker, E. D. (1993). Racial differences in the use of invasive coronary procedures after acute myocardial infarction in Medicare beneficiaries. *Ethnicity and Disease*, 3, 213–220.
- Gbadegesin, S. (2007). The moral weight of culture in ethics. In L. Prograis & E. D. Pellegrino (Eds.), *African American bioethics: Culture, race and identity* (pp. 25–46). Washington, DC: Georgetown University Press.
- Giacomini, M. K. (1996). Gender and ethnic differences in hospital-based procedure utilization in California. *Archives of Internal Medicine*, 156, 1217–1224.
- Ginther, D. K., Schaffer, W. T., Schnell, J., Masimore, B., Liu, F., Haak, L. L., & Kington, R. (2011). Race, ethnicity, and NIH research awards. *Science*, 333, 1015–1019.
- Gomes, C., & McGuire, T. G. (2001). *Identifying the sources of racial and ethnic disparities in health care use*. Unpublished manuscript.
- Griffith, D. M., Johnson, J. L., Zhang, R., Neighbors, H. W., & Jackson, J. S. (2011). Ethnicity, nativity and the health of American blacks. *Journal of Health Care for the Poor and Underserved*, 22, 142–156.
- Hammond, W. P., Mohottige, D., Chantala, K., Hastings, J. F., Neighbors, H. W., & Snowden, L. R. (2011). Determinants of usual source of care disparities among African American and Black Caribbean men: Findings from the National Survey of American Life. *Journal of Health Care for the Poor and Underserved*, 22, 157–175.
- Harris, L. (1992) Autonomy under duress. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 133–149). Washington, DC: Georgetown University.
- Harter, L. M., Stephens, R. J., & Japp, P. M. (2000). President Clinton's apology for the Tuskegee syphilis experiment: A narrative of remembrance, redefinition, and reconciliation. *Howard Journal of Communications*, 11, 19–34.
- Huey, S. J. & Polo, A. J. (2008). Evidence-based psychosocial treatments for ethnic minority youths. *Journal of Clinical Child Adolescent Psychology*, 37, 1, 262–301.
- Institute for Social Research. (2012). The National Survey of American Life: Coping with stress in the 21st century. Retrieved from <http://rcgd.isr.umich.edu/prba/nsal.htm>
- Johnson, P. A., Lee, T. H., Cook, E. F., Rouan, G. W., & Goldman, L. (1993). Effect of race on the presentation and management of patients with acute chest pain. *Annals of Internal Medicine*, 118, 593–601.
- Karlamangla, A. S., Merkin, S. S., Crimmins, E. M., & Seeman, T. E. (2010). Socioeconomic and ethnic disparities in cardiovascular risk in the United States, 2001–2006. *Annals of Epidemiology*, 20, 617–628.
- Katz, R. V., Kegeles, S. S., Kressin, N. R., Green, B. L., James, S. A., Wang, M. Q., . . . Claudio, C. (2008). Awareness of the Tuskegee Syphilis Study and the US presidential apology and their influence on minority participation in biomedical research. *American Journal of Public Health*, 98, 1137–1142.
- Kibler, M., Vigil-Otero, A., Sarpong, D., Lally, M., & Mayer, K. H. (2012). Correlates of willingness to participate in microbicide research among African Americans. *Journal of Health Psychology*. Advance online publication.
- Macinko, J., & Elo, I. T. (2009). Black–White differences in avoidable mortality in the USA, 1980–2005. *Journal of Epidemiology and Community Health*, 63, 715–721.
- Mayberry, R. M., Mili, F., & Ofili, E. (2000). Racial and ethnic differences in access to medical care. *Medical Care Research and Review*, 57(Suppl. 1), 108–145.
- Mays, V. M. (2001). Methods for increasing recruitment and retention of ethnic minorities in health research through addressing ethical concerns. *Proceedings of the Seventh Conference on Health Survey Research Methodology*. Washington, DC: National Center for Health Statistics, U.S. Department of Health and Human Services.
- Mays, V. M. (2011). The untold story of the legacy of the Tuskegee Study of Untreated Syphilis in the Negro Male or, is the legacy of Tuskegee affirmative action for White researchers? In R. Katz & R. Warren (Eds.), *The search for the legacy of the USPHS Syphilis Study at Tuskegee* (pp. 79–88). Lanham, MD: Lexington.
- Mays, V. M., Coles, C. N. & Cochran, S.D. (2012). Is there a legacy of the U.S. Public Health Syphilis Study at Tuskegee in HIV/AIDS-related beliefs among heterosexual African Americans and Latinos? *Ethics & Behavior*, 22, 461–471.
- Mays, V. M., Ponce, N., Washington, D. L., & Cochran, S. D. (2003). Classification of race and ethnicity: Implications for public health. *Annual Review of Public Health*, 24, 83–110.
- Mitchell, A. (1997). Survivors of Tuskegee study get apology from Clinton. *The New York Times*.
- Moutsakiis, D. L., & Chin, P. N. (2007). Why blacks do not take part in HIV vaccine trials. *Journal of the National Medical Association*, 99, 254–257.
- Nelson, A. (2002). Unequal treatment: Confronting racial and ethnic disparities in health care. *Journal of the National Medical Association*, 94, 666–668.

- Newman, P. A., Duan, N., Roberts, K. J., Seiden, D., Rudy, E. T., Swendeman, D., & Popova, S. (2006). HIV vaccine trial participation among ethnic minority communities: Barriers, motivations, and implications for recruitment. *Journal of Acquired Immune Deficiency Syndromes*, *41*, 210–217.
- NCVHS (2005). Eliminating Health Disparities: Strengthening Data on Race, Ethnicity, and Primary Language in the U.S. Accessed October 24, 2012 from <http://www.ncvhs.hhs.gov/051107rpt.pdf>
- Office of Extramural Research. (n.d.). Short-term courses in research ethics (T15). Retrieved from <http://grants2.nih.gov/training/t15.htm>
- Patient Protection and Affordable Care Act, Pub. L. No. 111–148, §2702, 124 Stat. 119, 318–319 (2010).
- Pellegrino, E. D. (1992). Response to Leonard Harris. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 150–158). Washington, DC: Georgetown University.
- Peniston, R. L. (2007). Does an African American perspective alter clinical ethical decision making at the bedside? In L. J. Prograis & E. D. Pellegrino (Eds.), *African American bioethics: Culture, race and identity* (pp. 127–136). Washington, DC: Georgetown University.
- Peterson, E. D., Shaw, L. K., DeLong, E. R., Pryor, D. B., Califf, R. M., & Mark, D. B. (1997). Racial variation in the use of coronary-revascularization procedures. Are the differences real? Do they matter? *New England Journal of Medicine*, *336*(7), 480–486.
- Peterson, E. D., Wright, S. M., Daley, J., & Thibault, G. E. (1994). Racial variation in cardiac procedure use and survival following acute myocardial infarction in the Department of Veterans Affairs. *Journal of the American Medical Association*, *271*, 1175–1180.
- Peterson, L. M. (1992). Response to Leonard Harris. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 159–164). Washington, DC: Georgetown University.
- Prograis, L., & Pellegrino E. D. (Eds.). (2007). *African American bioethics: Culture, race and identity*. Washington, DC: Georgetown University Press.
- Randell, V. (2012). Trusting the health care system ain't always easy!: Implication of an African American bioethical perspective. Retrieved from <http://racism.org/>
- Satcher, D., Fryer, G. E., McCann, J., Troutman, A., Woolf, S. H., & Rust, G. (2005). What if we were equal? A comparison of the Black–White Mortality gap in 1960 and 2000. *Health Affairs*, *24*, 459–464.
- Schulman, K. A., Berlin, J. A., Harless, W., Kerner, J. F., Sistrunk, S., Gersh, B. J. . . . Ayers, W. (1999). The effect of race and sex on physicians' recommendation for cardiac catheterization. *New England Journal of Medicine*, *340*, 618–626.
- Skloot, R., (2010). *The immortal life of Henrietta Lacks*. New York, NY: Crown.
- Slomka, J., Ratliff, E. A., McCurdy, S. A., Timpson, S., & Williams, M. L. (2008). Decisions to participate in research: Views of underserved minority drug users with or at risk for HIV. *AIDS Care*, *20*, 1224–1232.
- Smedley, B. E., Stith, A. Y., & Nelson, A. R. (Eds.). (2003). *Unequal treatment: Confronting ethnic and racial disparities in health care*. Washington, DC: National Academy Press.
- Thomas, L. (1992). The morally beautiful. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 118–126). Washington, DC: Georgetown University.
- Van Ryn, M., & Burke, J. (2000). The effect of patient race and socio-economic status on physician's perceptions of patients. *Social Science and Medicine*, *50*, 813–828.
- Williams, D. R., Haile, R., Mohammed, S. A., Herman, A. A., Stein, D. J., Sonnega, J., & Jackson, J. S. (2012). Perceived discrimination and psychological well-being in the U.S. and South Africa. *Ethnicity and Health*, *17*, 111–133.
- Wimberly, E. P. (2012). Ethical responsibility in healing and protecting the families of the U.S. Public Health Service Syphilis Study in African American men at Tuskegee: An intergenerational storytelling approach. *Ethics and Behavior*, *22*, 475–481.
- Wiredu, K. (1992a). The African concept of personhood. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 104–117). Washington, DC: Georgetown University.
- Wiredu, K. (1992b). The moral foundations of African American culture. In H. E. Flack & E. D. Pellegrino (Eds.), *African-American perspectives on biomedical ethics* (pp. 80–93). Washington, DC: Georgetown University.
- Woolf, S. H., Johnson, R. E., Fryer, G. E., Rust, G., & Satcher, D. (2004). The health impact of resolving racial disparities: An analysis of US mortality data. *American Journal of Public Health*, *94*, 2078–2081.
- Woolf, S. H., Krist, A. H., Johnson, R. E., & Stenborg, P. S. (2005). Unwanted control: How patients in the primary care setting decide about screening for prostate cancer. *Patient Education and Counseling*, *56*, 116–124.
- Working Group on Diversity in the Biomedical Research Workforce. (2012). *National Institutes of Health Draft Report of the Advisory Committee to the Director Working Group on Diversity in the Biomedical Research Workforce June 13, 2012*. The Advisory Committee to the Director. Retrieved from <http://acd.od.nih.gov/Diversity%20in%20the%20Biomedical%20Research%20Workforce%20Report.pdf>